CLL SUPPORT
Helping people affected by CLL and SLL

Newsletter

February 2022 Issue No.02

Bringing you the latest news and developments in CLL
Our helpline: 0800 977 4396

Welcome to our latest newsletter, and I hope you find it informative and useful.

The government announced that most Covid restrictions ended on 27 January. People will no longer have to wear masks on public transport and in shops, or use vaccine certificates, and the government has stopped asking people to work from home.
By 24 March, the legal requirement for people with Covid to self-isolate will end.

There has been little consideration, if any, of the 500,000 extremely vulnerable patients who will be affected by this. Many feel totally abandoned. We have been made aware of the anxiety felt by our members who are now being asked to return to their place of work. For these people, Covid certainly is not over.

The government announcement places blood cancer patients at particular risk, leading to even greater anxiety and stress.

We believe that the government should be talking about the fact that immunocompromised people are still vulnerable to Covid and explaining this to the public. The more people who wear masks and keep their distance in crowded places, the more immune compromised people will be able to lead a more normal life, to which they are fully entitled.

We are working with other charities, including Blood Cancer UK, to bring pressure on the government to acknowledge the stress placed on immunocompromised people by the relaxation of Covid rules.

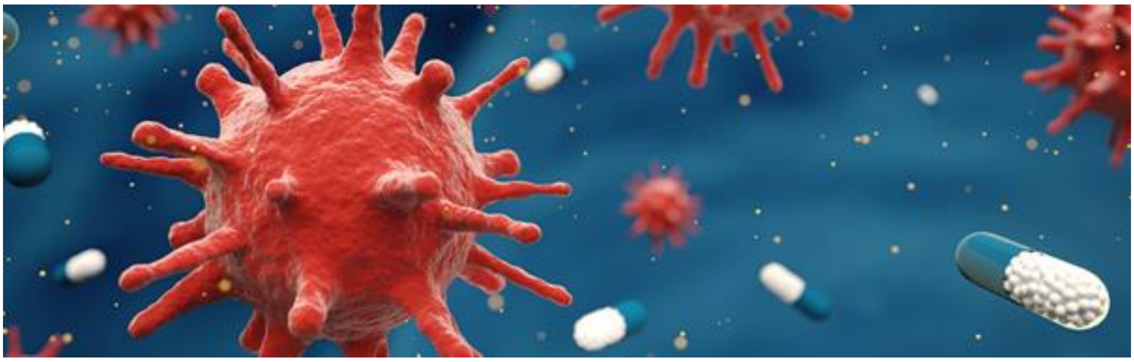
We want the government to take action to help protect these vulnerable people, which includes our members, by telling everyone about the immunocompromised and urging continuing wearing of masks and maintaining social distancing in crowded places.

We will continue to voice our concern and to do everything we can to protect our members.

Finally, please stay safe.

With best wishes
Marc Auckland
Chair of Trustees

Covid-19 update



Covid is still a great concern for many people.

We are constantly updating the information about Covid. There has been much confusion over treatment for CLL patients if they get Covid, and you can find the latest information and how to access treatment here .

We urge you to have a look at this to help prepare yourself if you get Covid.

Access to treatment for Covid by some CLL patients has been very difficult and is causing great anxiety. We support the views expressed in this BBC article here.

We are working with the charities mentioned to try to improve access to treatment for all clinically vulnerable patients. Please see the Latest news section below.

There is also lots of information on the recent webinar with **Prof Adrian Bloor**, including his answers on Covid from the Q & A session. Please see the separate section below.

Also, be aware of the symptoms of Omicron, which can differ from the Delta variant.

- **The five main symptoms of Omicron are more like those associated a cold, including: sore throat, runny nose, headache, fatigue and sneezing.** Smell and taste may be normal. Some people also reported loss of appetite and 'brain fog'.*
- * Data taken from the Zoe study.

What can I do to protect myself and others from Omicron?

It's still important to remain vigilant:

1. Recognize ALL of the symptoms of Omicron, get tested and isolate when you experience them. You may wish to ask people with whom you will come into close contact to have a lateral flow test before seeing them.
2. If you live in an area experiencing high rates of infection, consider staying home and reducing social contact.
3. Make sure you and your close contacts are fully vaccinated (3 shots of the vaccine for most people, **4th jab for clinically vulnerable)**.
4. Wear a mask in crowded places. See below for information on the best masks.

   In addition, the usual frequent hand-washing and social distancing recommendations are still relevant.

'Plan B' restrictions have come to an end.

- **What does this mean in practice?** Masks and Covid passports will no longer be required by law.
- **Do I need to wear a mask in supermarkets?** No, this is no longer required, but we recommend that you carry on using a mask to help protect yourself and others. Some supermarkets are still urging masks for everyone, including staff.
- **Do I still need to wear a mask on public transport?** Mask wearing remains in place on London Transport only.
- **So, what restrictions remain in place now?** You still need to book and pay for a test, either lateral flow or PCR before you leave England, and take another when you return. On February 11, this will be scrapped for people who are fully vaccinated.

Please note that different rules may apply in the devolved nations, but we understand that there is a move to harmonise all regulations to ease confusion.

Latest News!

Along with other cancer charities, we have been lobbying for a change in the access to Covid treatment for the clinically extremely vulnerable. We are pleased that the government has announced that from **10 February 2022**, a PCR test will no longer be required before treatment, and a lateral flow test can be used.

This has been the cause of much anxiety and distress to patients, and we are very pleased that this decision has been taken.

Our latest webinar with Prof Adrian Bloor is now available on video. **You can see it here**.

Professor Bloor is Consultant Haematologist and MAHSC Honorary Clinical Chair, University of Manchester.

He is in discussion with one of our trustees, Lewis Troke. The topic was:

"End of the Pandemic:
Living with Covid & CLL/SLL as the New Normal"

Some of the topics Prof Bloor covered were:

- New Covid treatments such as Regeneron.
- How do I get access to the new Covid treatments?
- What should I do if I test positive?
- What impact does Covid have on CLL patients?
- Is there still a threat from the Delta variant?
- Are we entering a 'new normal' for CLL patients?
- Coming out of remission. What are the steps?
- Approaching second treatment. What are the options?

If you missed this very interesting and informative webinar, or if you want to have another look, you can catch-up here**. We are extremely indebted to Prof Bloor for stepping in at short notice and for a most engaging and informative talk. He answered every single question, either on the day or in a follow-up which you can find** here**.**

Make a date in your diary for our next webinar

Tuesday 15th March with Professor Chris Fegan

Details to be announced soon.

Can you help, please?

Would you help another CLL patient?

We partner Leukaemia Care in a 'Buddy' scheme, which helps CLL patients to come to terms with their diagnosis. Each Buddy helps another patient simply by talking to them, usually over the 'phone.

There is an urgent need for new Buddies, particularly if you are on 'Watch and Wait', although you would be welcome if you are on or have completed treatment. In particular, one patient with CLL and ME would love to hear from someone who also has these conditions.

Full training is given and if you would like more information about this very worthwhile and rewarding venture, please contact the project leader, **Kay Drew** at: kay.drew@leukaemiacare.org.uk

Thank you

We mentioned in the last newsletter about the importance of Vitamin D, particularly in Winter months. An interesting paper published in the British Medical Journal (BMJ) shows that high levels of vitamin D may protect against auto-immune disease in over 50s. We know CLL patients can suffer from autoimmune disease, but please note that this was not a trial involving CLL patients specifically.

This trial of 26,000 participants showed that a dose of 2000 international units (IU) of vitamin D per day reduced the development of autoimmune disease by 22 per cent, compared with a placebo. This is a larger dose than the standard 400 IU recommended by health organisations such as the UK's Department of Health and Social Care. You can find the full paper here.

The Mayo Clinic is conducting a separate trial on CLL patients and vitamin D, and we hope to report on that when it's published.

Please note, you should always check with your consultant before taking any supplements. Some supplements may affect the treatment you may be receiving.

World
Cancer Day
4 February

World Cancer Day is 4 February 2022.

This year’s World Cancer Day’s theme, “Close the Care Gap”, is all about raising awareness of this equity gap that affects almost everyone, in high as well as low- and middle-income countries, and is costing lives. We will joint other charities to speak out and stand up for those burdened with cancer.

A patient's story

In the previous newsletter, we began a story from one of our members. If you missed part one, you can catch up here.

Jim’s story. Part 2.....

Tuesday 26th October, 7pm.

"I’ve got the bone marrow results, its over 90% full of CLL cells".
"Is that bad?" I ask. Stupid question. "Yes, its very high, we would normally start treatment at 50 -60%. I have booked you in to start chemotherapy on 9th November, the nurse will be in contact to let you know the details". The noise you can hear is my ego crashing to the ground.

To cap things off I catch a cold and have my covid booster. I can't recover from either and by the 8th of November it’s as much as I can do to walk up the stairs to go to bed.

Watch and Wait is well and truly over.

9th November 2021, Chemo start day. I am on a new treatment, only approved for use by NHS in November 2020, it’s an immunotherapy that targets the cancerous white cells directly, not like conventional chemo that attacks everything (my interpretation).

Day 1 is a small infusion of Obinutuzumab, I still can’t pronounce it, so called it ‘Obi1knobe’. It takes most of the day to finish the small dose, but I am ok.

The results are staggering, the first night my white blood cell count drops from 350 to 50. I'm euphoric, "this will all be over by Christmas", to coin a phrase (but it’s not over by Christmas, not by a country mile)

The following day I have the big infusion, it’s a long day because of the slow rate. Everyone is so kind, it is very humbling.

The following morning my blood tests show the white blood cell count at 4, that’s normal, I am released from the ward and return home on a steroid induced high. "This is a doddle".

Friday morning, reality strikes, I've changed colour, or colours to be precise, I seem to shimmer between yellow, green, and translucent grey. I feel absolutely wasted, it's definitely a bed day..... and so is Saturday and Sunday, Monday arrives, blood test before next infusion on Tuesday. I've lost another 8lbs in weight in a week, I am now hovering at just over 11 stone, I haven't been at this weight since I was at school. This is a low point in every way.

After three weeks of Obi1knobe, the venetoclax tablets are introduced. The venetoclax dose is increased over a five-week period, the long and short of the tablet increase is: blood tests, tablets, blood tests, lots of water, feel rubbish, lots of wee, feel better .... repeat.

I mentally crash during Christmas week. If it wasn’t for the support of my fantastic wife things could have become very dark.

But we move on. I am now on the daily maximum venetoclax. I don’t feel exhausted anymore, I have the occasional 'lie in front the telly day', but in the main I feel ok.

I have 10 months of treatment left but am looking forward, I've ordered an ebike, I will get my energy and fitness back and consider myself hugely fortunate to have been given this new and very expensive treatment.

I have met the most incredible people who work in the hospitals every day to help us get through our problems. I don't have the words to describe just how wonderful they are, but would like to thank them for all the help and support they have given me.

My recovery is now in my hands, I have been given the opportunity to return to being a psycho mountain biker again and I intend to grab it with both hands.

The thing with CLL is it affects everyone differently and the treatment also affects everyone differently. I am lucky that I did not experience severe symptoms until the last few months of watch and wait and my reaction to the drugs has not been too bad, it could all have been so much worse.

As you will have probably gathered, I have been in denial from the start, and failed to engage with the process at virtually every stage until I was lying on a hospital bed looking like a pin cushion. This approach has worked for me, yours will be different, there is no right or wrong.

I hope this story helps you to understand a bit about living with CLL and gives you some insight that there are challenges to overcome and optimism that life (even a very active life) is possible on your CLL journey.

A postscript for the season finale:

I have just (Jan 13th, 2 months after starting chemo) done 11 human powered miles on a mountain bike and I feel elated, on a high.

I'm actually feeling pretty emotional as well.

I cannot believe how transformative this treatment has been. it should be a huge message of hope for everyone with CLL.

Thanks for reading
Jim

Don't forget!
We rely on donations from our members to help us to carry on our work
There are easy ways you can 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!

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.

You can contact us at membership@cllsupport.org.uk

We look forward to hearing from you!