CLL SUPPORT
Helping people affected by CLL and SLL

# Newsletter

January 2022 Issue No.01

**Bringing you the latest news and developments in CLL**

**Our helpline: 0800 977 4396**

**Welcome to our first newsletter of 2022, which gives me the opportunity to wish you a very happy and healthy New Year.**

Almost exactly two years ago we published our first newsletter covering the then new Covid-19 outbreak. None of us could have imagined that we would still be featuring it today. It has occupied all our lives to a huge extent during the intervening period. However, there are some encouraging positive signs emerging, as you will see in this newsletter. New treatments and, above all, vaccinations, have brought significant hope that the situation will improve.

Throughout this very difficult period, we have tried to keep you informed of developments in CLL, particularly advances in treatments, and we will continue to do so. Our new mental wellbeing website, CLL Support ACT, has proved very popular, and we hope to be able to announce other developments along the same lines later in the year.

We are currently planning our popular webinars for the year, and I am very pleased to welcome back Dr Ben Kennedy to be the keynote speaker in the first, which will be on

January 20th. Dr Kennedy is a very engaging speaker, and we hope you will be able to join us for what I am sure will be an interesting and informative discussion.

As always, we love to have feedback from our members, so if you would like to comment on any aspect of our work, please feel free to do so. If you have a story about your CLL you would like to share, please contact us. These experiences are very much valued by members and do help others to understand that they are not alone.

Finally, please stay safe.
With best wishes
Marc Auckland
Chair of Trustees

## Covid-19 update

**Since the last newsletter, more information about the Omicron variant of Covid-19 has become available.**

Although it is still very early in the development of the virus, and we need to be cautious, some facts are beginning to emerge. It seems likely that:

- Omicron is much more infectious than Delta. Some estimates put this at several times more, perhaps even up to ten times more.
- It seems to result in milder infections, but can still lead to hospitalisation, particularly for the immunocompromised.
- **Omicron symptoms** can differ from the Delta variant. **The five main symptoms 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'.*
- The fourth vaccination now becoming available offers greatly increased protection.*

* 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.

## What should I do if I catch Covid-19?

Even after taking all necessary precautions, you could still catch the virus. There are a number of important precautionary steps you could take beforehand, and we strongly recommend that you consider these.

- **Make sure that your medical team - including your GP have coded your medical records as someone at "High Risk".** This will mean that you will automatically be sent a PCR test by the NHS to keep in case you suspect you have been infected. You will also be given priority for antiviral treatment. All CLL patients are in this category. If your records have not been coded correctly, it may take time to have them corrected, so:

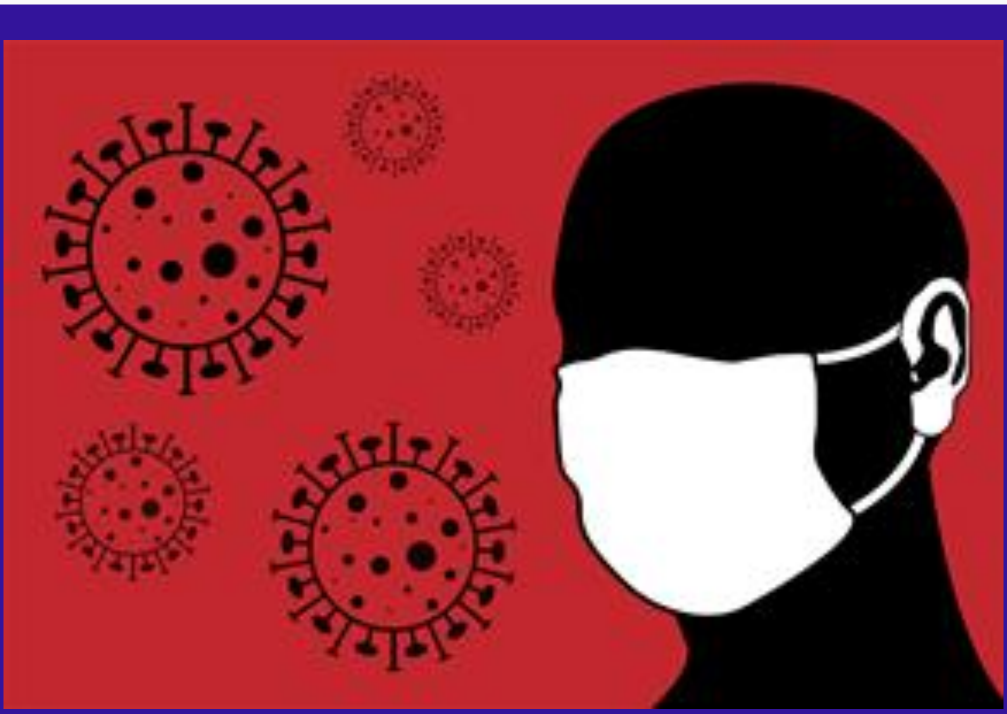
- **Order a PCR test and keep it at home in case of infection.** You can obtain this from your GP or by telephoning 119. **Important:** To qualify for antiviral treatment you will need a positive PCR test. **This should be a Priority Test and labelled accordingly, as this will be processed more quickly.**
- **It's important to have one of the antiviral treatments as quickly as possible after a positive test, usually within 5 days.** In the event of a positive PCR test, you should contact your GP or medical team for referral to the **Covid Medical Distribution Unit (CMDU).** If out of hours, call 111.

The antiviral treatments (including monoclonal antibodies) are very effective, but need to be administered within days of a positive test.

## What type of mask to wear?

There is good clinical evidence that wearing masks offers protection against Covid-19, for example, the Oxford University study here.

The question is: which one should you choose?



There are various standards for masks:

- Face coverings such as home-made masks may give some, but probably very little, protection to the wearer.
- Medical grade/surgical masks (typically blue) are designed to protect others, rather than the wearer. Look for the CE mark and EN standard 14683.
- Protective masks like FFP1, FFP2 and FFP3 (equivalent to N95) are designed to protect the wearer as well as others. Look for the CE mark and EN149. These masks are more expensive but can be worn up to about ten times and continue to give good protection (up to 98% filtration rate). We recommend using these if possible.
- It's also important to wear the mask correctly so that it fits tightly, especially around the nose and at the sides. Also, avoid touching it as far as possible.

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## Our next webinar! Make a date in your diary.

Register here: webinar@cllsupport.org.uk

**January 20 2022 at 1.00 pm**

**Join from 12.45**

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

**Our keynote speaker will be Dr Ben Kennedy, who is Consultant Haematologist at Leicester Royal Infirmary.**

**Some of the key questions**
**Dr Kennedy will be tackling:**

- 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?

**We will close at 2.30 and there will be plenty of time for questions.**

**We look forward to welcoming you!**

****If you are unable to attend, don't worry, the webinar will be recorded and placed on our website a few days later.****

**Please register your interest at:**

webinar@cllsupport.org.uk

## Vitamin D

A quick reminder that Vitamin D is important for our health. However, because the body can't store vitamin D, it may be necessary for some people to take a supplement. Our bodies create vitamin D from sunshine, which is in short supply during Winter months, and this may lead to low levels. The NHS recommendation is a 10mcg daily tablet during the Winter. It may be worth asking your doctor at the next consultation to check your vitamin D level and see if a supplement would be helpful. Please do not start any supplements without first consulting your medical team.

Vitamin D is also found in the following foods:

- oily fish – such as salmon, sardines, herring and mackerel
- red meat
- liver
- egg yolks
- fortified foods – such as some fat spreads and breakfast cereals

## A patient's story

**Our patient's story in this issue is longer than usual, so it's split into two parts. Look out for Part 2 next time.**

### Jim’s story. Part 1

November 2015

"I need another wee", that's how it all started. Four simple words. "Go to the doctor and do something about it", my very much better half insists.

Yep, it’s that time of life, I'm 57.I book an appointment to see the doc. They take some blood.

Imagine my surprise when the following day I get a call from the surgery, "Hello Mr. H" "the doctor would like to see you today, can you come down at 6 o’clock?"

“Wow”, I'm thinking, “that was quick, I've been fast tracked, I must be special!”
The doc says: "There's no easy way to say this, you have Leukaemia, I'm referring you to QMC, they’ll be in touch".

All thoughts of the original reason for the visit are completely forgotten. I'm not sure this is a fair swap, go in for something to stop me peeing, come out with cancer.

One week later - the NHS move very quickly when there's lumps or the big C involved - I'm sat in front of a consultant.

"You have CLL, it’s the most common form of Leukaemia. You are very young.” (I like her). “It’s very early stage and you are very fit.” (I like her again). “We don’t usually treat this until your symptoms reach a certain level. We’ll keep an eye on you. It's best to try and ignore it and live your life as normally as you can, you will probably die of old age" Sounds good to me, nothing to worry about then.

Excellent, I feel fine, no symptoms. So that's what I did, carried on as normal, rode my bike, went to work, did DIY stuff and every six months went for my check-up.

After a few years we did the maths, and decided we had enough saved to retire and we did just that, packed in work, upped sticks and moved to the retirement capital of England, Eastbourne., This turns out to be MTB heaven, so I was out on my bike pretty well every day and considered myself super fit.

I'd been going for my six monthly regular check-ups, obviously ignoring the results and the suggestions that I should move to testing every three months, "as your white cells are doubling every nine months".

My white cell numbers were, however, high, over 250, (normal is 4 to 11), platelets and haemoglobin have dropped, but I still feel good. When we go to see the new consultant at Eastbourne hospital, in November 2020, I again hear, "everything's fine", my wife hears "you are probably a year away from starting chemotherapy", funny how different the ears are.

Well 2021 was 'interesting', covid aside, it really charts the decline everyone warns you about, until you reach a point where you know 'watch and wait' is over and you are ready for treatment.

Anyway for me, in my little denial bubble, I was enjoying myself, I joined a local MTB club. Great, but come July, I was surprised to find that everyone else's fitness was much better than mine. Instead of the lead group I was usually at the back and being left behind.
I was also beginning to feel very tired, have pains in my groin and my weight started to drop seriously.

I was advised by my wise and sensible wife to contact haematology and ask them if there is anything going on - she being aware of what was actually happening.

Bloods come back, a 'slight' increase in white blood cells, now 300, and platelet and haemoglobin levels have dropped some more. Doc: "I'd like to do a CT scan of your abdomen and take a bone marrow sample".

This was September. For any normal person alarm bells would now be ringing. For me, the white cell count’s only gone up 20%, so its slowed down. I'm booking up MTB events for October and planning which events I can get to in 2022.

The CT scan results are in, "you have swelling in your lymph nodes and spleen, I definitely want to do the bone marrow test.” Apparently, she also added "If this comes back with a high reading, we will need to start chemotherapy straight away". Obviously, I didn’t hear that, but my ever-vigilant wife was on the case.

October 23rd, I am on the way to Swanage to do a 45mile MTB event, only I don’t. I have to pack up at 30 miles and limp back to the start. I feel completely drained. Perhaps it's time to start taking this seriously.

By the time I get home, everything in my little bubble brain is back to normal, it was just a bad day, too much travel, not eating correctly and a bad night’s sleep. I haven't heard back about the bone marrow test so it can't be anything serious......

To be continued in Part 2 in the next newsletter.

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## Don't forget!

**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!**