CLL SUPPORT
Helping people affected by CLL and SLL

Newsletter

March 2022 Issue No.03

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.

I trust that you are well and coping with the very difficult times we are all facing.

The weeks since Christmas have been extremely busy for us as we worked to make the voice of blood cancer patients heard by the government and the NHS. We were very concerned that many blood cancer patients had been overlooked for both their booster Covid vaccinations and for access to Priority PCR tests, which allow quick access to essential treatment.

We found that the problem was that many CLL patients had been wrongly coded on their medical records or, in some cases, not coded at all. This meant that these CLL patients were not being recognised as 'clinically extremely vulnerable'.

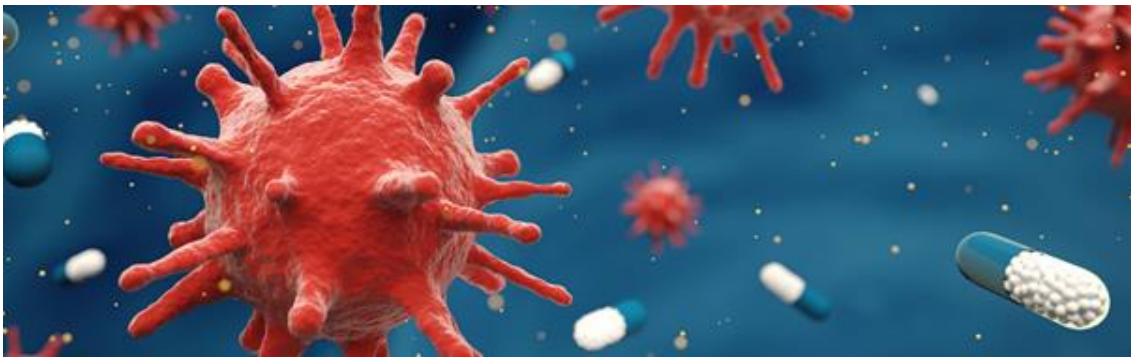
Thanks to the response from our members we were able, along with other blood cancer charities, to present our findings to NHS Digital. I am very pleased to say that NHS Digital responded to our intervention, and corrections were made to many patient codes. The work is ongoing.

However, our efforts on behalf of our members are by no means over, and the recent announcement of the early scrapping of Covid restrictions in England brings new concerns. You can find more details of what we are doing about this in this newsletter, and you can be sure that we will continue to work on behalf of our members and blood cancer patients generally.

Wishing you good health.
Marc Auckland
Chair, CLL Support.

Covid-19 update

Covid is still very much with us. Here is a summary of the current situation.



Covid rules in England abandoned.
Scotland, Wales and Northern Ireland set to reduce restrictions.

You can find the full changes, and how they affect you, on our website here

We are constantly updating the information on the website about Covid as conditions and rules change.

COVID Treatments

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. This is even more important as restrictions are being reduced.

Access to treatment for Covid by some CLL patients has been very difficult and is causing great anxiety. We are working with other charities to try to improve availably of treatment for all clinically vulnerable patients.

One of the key problems has been incorrect or no coding of the patient on their medical records. You may wish to check with your GP that you are properly coded.

The main code (known as SNOMED codes) for CLL is 277473004, but there are several others, depending whether you are having treatment, or on medical monitoring (watch and wait). It's important to get the correct code to be able to access testing and treatment. You can find derails of the coding on the NHS Digital website here.

There is also lots of information in the recent webinar with **Prof Adrian Bloor**, including his answers on Covid from the Q & A session. You can find the video of the webinar here.

Omicron symptoms can differ from the Delta variant.

- **The five main symptoms of Omicron are more like those associated with 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. You can find our recommendations about masks in a previous newsletter here

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

It's still so important to remain vigilant!

CLL Support cooperates with other blood cancer charities and organisations to raise important issues. Our voice is stronger together.

We are pleased to announce the launch of the **Patient Impact Statement** of the **International COVID-19 Blood Cancer Coalition (ICBCC)**. The coalition has prepared the Statement for use in different countries to help when advocating for the provision of anti-COVID-19 treatment and care for immunocompromised or immunosuppressed (IC/IS) blood cancer patients. The Statement has been endorsed by multiple networks and national organisations of the global patient advocacy community as well as renowned medical societies and representatives from the global clinical community. We are very pleased to have been part of this coalition.

You can find this important statement in full, together with all the contributors, here.

Please consider sending a copy to your MP.

Make a date in your diary for our next webinar.

Tuesday 15th March with Professor Chris Fegan.

1.00 pm - 2.30 pm. Join from 12,45 pm

'Let's talk about Living well with CLL'

We are delighted to be able to welcome back Professor Christopher Fegan who last spoke for us in Cardiff at the start of 2020 - just before the Covid pandemic closed everything down.

Joining him will be Dr David Allsup, Senior Lecturer in Haematology who has an Honorary NHS appointment with Hull and East Yorkshire Hospitals NHS Trust. He is the local lead for chronic lymphocytic leukaemia (CLL), in which he has a longstanding research interest.

And we are especially pleased to have Haematology Specialist Nurse Julia Evans, from the Oxford Cancer and Haematology Centre, Churchill Hospital, who works with early stage patients all of whom are pre-treatment. She will be sharing insight into how the 'OxCom' service, which is a collaboration with GPs in Oxfordshire to monitor all CLL/MBL patients, was developed.

****Please register by emailing:** webinar@cllsupport.org.uk**

Prof. Chris Fegan is Emeritus Professor, University of Cardiff School of Medicine.
Prof Fegan has retired from day-to-day practice, but still plays a very active role in CLL research and teaches at the University of Cardiff, School of Medicine.

Dr David Allsup is Senior Lecturer in Haematology and has an Honorary NHS appointment with Hull and East Yorkshire Hospitals NHS Trust. He is the local haemophilia director with additional clinical interests in inherited and acquired platelet disorders. He is also the local lead for CLL.

CNS Julia Evans, is CLL Specialist Nurse, Oxford Cancer and Haematology Centre Churchill Hospital. Julia works with early stage CLL patients all of whom are pre-treatment. She monitors and supports patients, mostly over the telephone, in a clinic known as OxCom- a collaboration with Oxfordshire GPs. She also works in the general haematology clinic assisting patients being investigated for possible haematological conditions.

Please register by emailing: webinar@cllsupport.org.uk

Can you help, please? (1)

Call for members in the Devolved Nations to get involved

One of our Trustees within the team has taken on the responsibility for matters pertaining to CLL and related health issues within the devolved nations.

John Greensmyth is resident in Scotland but he also keeps a watching brief of Wales and Northern Ireland. The scope of this tasking involves attending (virtual) meetings on behalf of CLL Support and monitoring various Government publications and related sources of information. This often includes representing the patient voice on a variety of platforms - this can be as simple as relating patient experience to a panel during a discussion topic or advocating on behalf of patients wherever possible.

John's role is wide ranging and he would benefit from some help! Some on the ground presence with local knowledge in each of the devolved nations (inc Scotland) would be appreciated. No qualification is required and a willingness to help in a constructive manner is the simple job specification. A few spare hours every so often is the only burden. John will offer guidance and he is happy to explain the scope in more detail to any willing volunteers. The pay-back is the feel good reward of 'doing my bit to help' and we will all benefit in the longer term.

Anyone interested in finding out more should contact John by email: john.greensmyth@cllsupport.org.uk

Can you help, please? (2)

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

A job opportunity!

Come and work with us.

We currently have an opening for a home-based, part-time, donor relations and administration person to support our coordinator.

The role is for the equivalent of two days a week, to be worked flexibly across the month, and the annual salary will be in the region of £10,000.

Interested applicants should request a job description and submit their cv with a covering letter to Sarah Tobin
at: coordinator@cllsupport.org.uk
by 31st March 2022.

A great opportunity to take part in one of the most popular cycling events in the UK - Ride London! Enjoy a great day out and help CLL Support at the same time!

Places for this event are very scarce, but we have managed to secured five places on this iconic cycling event to be held in London and Essex on May 29th 2022.
We have already filled three of the places and seek to complete the group by enlisting two other cyclists. Entry is free but you must raise £350 in

sponsorship using the dedicated Enthuse fundraising platform.

If you or anyone you know would like to take on this 100 mile challenge, then please contact us at:

coordinator@cllsupport.org.uk

More fundraising news!

We rely greatly on donations and fundraising by our members, without which we could not carry on our work on behalf of CLL and SLL patients. Our thanks go to everyone who helps.

Anne Kemp

Anne Kemp's South West Coastal Path - walking back to normality and raising funds for CLL Support!

Anne says:

In March 2020, I started walking the Pennine Way (270 miles), motivated by a diagnosis of CLL. I didn't realise then I was walking into 2 years of effective shielding. I stopped 4 days into the walk due to lockdown, but finished the remainder of the walk that August, raising £8600. A phenomenal amount and a phenomenal experience.

Now I want to walk back to normality over 52 days in April/May along the South West Coastal Path (630 miles) and apparently the equivalent ascent/descent of 4 Mount Everests.

It’s been a long haul the last 2 years not meeting friends and colleagues, and my family have made huge sacrifices to keep me safe ... as well as putting up with my increasing hermit behaviour. But that's the point - I am safe and I am well.

You can support Anne and help us here.

Thank you!

There is another way you could help

Our new free Will-writing service.

We do understand that the decision to write a will can be a delicate topic and must be handled sensitively. But it is essential for most people to have a will in order to safeguard their interests after death.

It would be wonderful if you could read on before deciding if this is something you wish to 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.

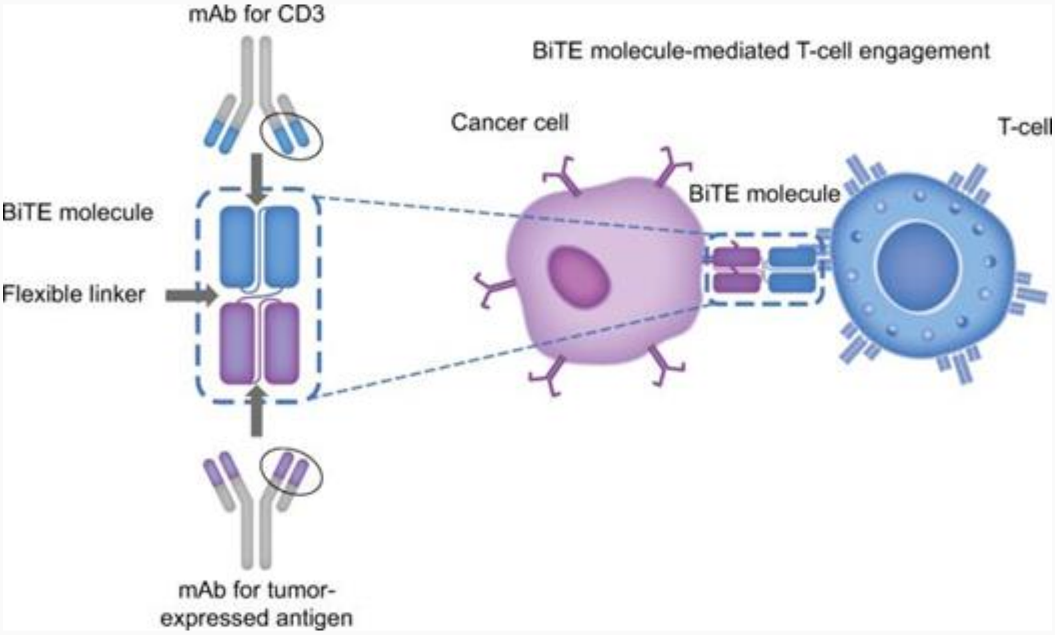
3. The Network send you a list of your nearest participating solicitors and a voucher to take to your appointment.

4. You meet with the solicitor at an office local to you (or online if you prefer) 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 discrete and 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:

A patient's story



This is a patient's story with a difference.

One of our valued administrators on our online forum, Health Unlocked, is about to undergo a new type of treatment (BiTE) for CLL. This is really cutting edge therapy which is of great interest to all CLL patients, and we will be reporting on their progress. We think this makes compelling reading.

Some members may not be familiar with the technical terms used, and we give a short explanation at the bottom of this story.

"I was diagnosed with CLL in June 2013 after concerns were expressed by my colleagues about my bruising. At the time I was the Biomedical Healthcare Scientist Laboratory lead and clinical trials Manager for a large Trust and so my blood was taken and the diagnosis was made in my own laboratory.

The next day I was seen in the Haematology-Oncology clinic of a neighbouring Trust and I had a bone marrow biopsy. That confirmed both the immune thrombocytopenia and CLL. Because my platelets were very low at 23, and I had refused steroids, I was seen twice a week for the next few weeks and eventually they started to rise. I was told I had the11q del mutation and that my IGHV was unmutated.

I had two and half years with a steadily rising lymph count and eventually it was the size of my liver, spleen and abdominal nodes that triggered treatment and I started Ibrutinib and Rituximab in October 2015 in the FLAIR trail. The first few years were hard and those of you who take Ibrutinib will know how unrelenting the cramps, arthralgia and diarrhoea can be. As a bonus I found myself in AE with my blood pressure at 230/74, another gift from Ibrutinib, and I still take blood pressure tablets to this day

I was aware that the treatment period was for six years but I felt confident that by then Ibrutinib would be approved for first line use and I would be able to continue taking it if I was still in remission. Well, 6 years flew past and that wasn't to be. I was feeling really well and in a great complete remission, albeit with very low levels of CLL cells in my blood. I was anxious about stopping Ibrutinib but was reassured by my consultant and the anecdotal experiences of others, that my remission was likely to continue for quite a few years before I would need to resume treatment. In the background I was working with the people trying to get the new STATIC trial off the ground in the hope that I could help the FLAIR participants get continued access to Ibrutinib at the end of their six years.

As per the trial protocol (and funding) allowed, my Ibrutinib was stopped just before my birthday on 13th October 2021. Within 5 days I had a 6cm LN come up under my left arm and smaller ones in my right armpit. I saw my doctor a week after stopping and he was shocked by my rapidly enlarging LNs but especially the left one. He immediately said that I may have developed Richter's and that I needed a CT scan, biopsies and possibly a PET scan. I had a CT scan and three core biopsies within 2 weeks but the biopsies showed just CLL.

In late November my Dr was given permission by NHS England to prescribe Acalabrutinib for me but it had no effect and my CLL continued to progress with several of my abdominal LNs now approaching 7cm in diameter

My doctor was not reassured by the core biopsy histology because my blood results continued to show a high LDH and the LNs were still enlarging so he ordered a PET scan, but I waited 4 weeks for that. It was reported as probable Richter's because the left axilla was very hot on the scan. He still wasn't sure because I felt too well to have Richter's so we then decided that that ‘hot’ LN needed to be surgically removed for a proper histology report. I then waited another 4 weeks for the surgery as they originally booked me in for the wrong procedure and it finally took place on 11th January. I waited 2 weeks for the report and I had another CT scan whilst waiting.

The lymph node histology showed highly proliferating CLL but thankfully no Richter's. CT following a couple of months of Acalabrutinib showed progression with several abdo LNs at almost 10cm. Genetic studies revealed that I also have two BTK mutations which are acting synergistically to promote cell proliferation and evade the BTKi. That's in addition to the 11q del and ATM deletion but thankfully no TP53 issues

I was feeling very down and defeated by the stress of the situation and that it had been going on, with no clear forward plan for several months now, and I needed another treatment asap . My Dr knew I didn't want to use my VR option if there was another available and we were both hoping I could join their VR +/- Loxo trial but it was now clear that it wouldn’t be open in time for me. So, he suggested a ROR1-bispecific T cell engaging antibody treatment at Royal Free/UCLH with Dr Parag Jasani. This is a first in human trial and only 6 patients in the world have received this treatment as part of the dosing study at UCLH/Royal Free.

The theory is that the bi-specific antibody engages the T cells with the CLL cells and they kill them. It's a sort of 'off the shelf' CAR-T with all the same side effects of cytokine release syndrome, tumour lysis syndrome and immune effector cell-associated neurotoxicity syndrome (ICANS).

I wrote a post about Bispecific T cell engaging antibodies here: healthunlocked.com/cllsuppo...

Almost two weeks ago I underwent the screening tests for the study and yesterday I heard that I've been accepted. I will have a PICC line inserted and be in hospital for 5 days for the first course so that I can be closely monitored for the side effects that I mentioned in the previous post and I must admit to being nervous because with my bulky disease it's more risky.

The study's called the NVG111-101 trial uclh.nhs.uk/news/uclh-resea... It's a continuous infusion for 3 out of 4 weeks and then start again with a weekly visit to London to top up the pump and be assessed. We don't know if this treatment this will definitely work for me but if, after 3 months, it appears that it is, then I will receive another 3 months of treatment and be followed up for almost 3 years.

I'm hoping to avoid the worst of the side effects and I'll update as and when things happen."

We would like to take this opportunity of wishing our administrator well with this potentially ground-breaking therapy for CLL..

A few of the terms used in this story:

Immune thrombocytopenia, or ITP, is a bleeding disorder. In ITP, the blood doesn't clot as it should. This is due to a low number of blood cells called platelets.

IGHV mutation. CLL patients with unmutated IGHV genes have a less good prognosis with conventional chemoimmunotherapy than those with mutated IGHV genes. Patients are usually tested for this prior to treatment.

LN: Lymph Node(s) For more information about your lymph system, click here.

Richter's: This is a transformation of CLL into a more aggressive disease which has a much less favourable outcome.

BTKi: Ibrutinib is known as a BTKi inhibiter. Bruton Tyrosine Kinase (**BTK**) inhibitors inhibit the enzyme **BTK**, which is a crucial part of the B-cell receptor signalling pathway. Certain B-cell leukaemias, such as CLL, use B-cell receptor signalling for growth and survival.

PICC Line: A PICC line (Peripherally Inserted Central Catheter line) is used to give chemotherapy treatment or other medicines. A **PICC line** is a long, thin, hollow, flexible tube called a catheter. It is put into one of the large veins of the arm.

CAR-T: A new treatment where a patient's own blood cells are removed, treated and returned. A good summary of CAR-T can be found here.

Welcome!

A warm welcome to Matt Gibson, who has joined us as an Associate Trustee.

Matt has been very active in our Under 60 Club, is a CLL patient and 5 years post FCR treatment.

He is a keen runner.

We very much look forward to working with Matt.

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 Leukaemia Support Association - when registering.

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

easyfundraising feel good shopping smile.amazon.co.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 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!