CLL SUPPORT
Helping people affected by CLL and SLL

Newsletter

November 2022 Issue No 10

Bringing you the latest news and developments in CLL and SLL

Our free helpline: 0800 977 4369

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

It's been a very busy time since our last newsletter.

Our main event was the very successful Glasgow conference, and our thanks go to all our contributors, especially to our keynote speakers, Dr Alison McCaig and Pinky Agrawal, for giving their time so generously. Our three patient speakers were very impressive in their determination to 'live well with CLL', and I thank them also. You can find a link to the conference recording later in this newsletter.

This was our first conference for over two years, and the first we have live-streamed. We are encouraged by the response and have already planned our next conference which will be in **Birmingham on 3rd December.** You can find details below.

In addition, we launched the findings of our survey, which will guide us in making decisions for the future. Again, details are below. We have also been working closely with our charity partners One Cancer Voice, and the Blood Cancer Alliance to try to keep cancer care at the top of the government's agenda.

Meanwhile, your charity needs you!! We are making good progress in recruiting Trustees and Associate Trustees to take over from those of us who have been Trustees for as long as we are permitted. However, we still need a few more volunteers.

I mentioned at the Glasgow Conference that **Hilary Lindsay** (hilary.lindsay@cllsupport.org.uk) will be taking over from me as Chair next April and **John Greensmyth** (john.greensmyth@cllsupport.org.uk) will become Vice Chair. They want to rearrange our activities so that not too many demands are made of any one trustee. In particular, they would like to set up a **Conference and Webinar team** and a **Newsletter and Website team**. If you might be interested in joining either of these, or if you would just like to get more involved with us, please have a chat with Hilary or John.

We simply can't function without trustees, so any help you feel able to give would be really appreciated.

Finally, thank you again for your support, and I wish you good health.

Marc Auckland
Chair, CLL Support

Our first conference for over two years!

Our first conference for over two years was held in Glasgow recently. The topic was:

'Managing CLL in 2022 - Treatment guidelines explained'

We were privileged to have some excellent speakers and the topics discussed were very relevant to all people with CLL, their families and supporters. You can find video recordings of all the talks here:

Glasgow conference videos

Our next conference! Birmingham 3rd December

Join us to hear Prof. Paul Moss, who is Professor of Haematology within the Institute of Immunology and Immunotherapy at the University of Birmingham.
Professor Moss led the UK Coronavirus Immunology Consortium (UK-CIC) that brought together leading immunologists from 20 UK universities to understand the immune response to SARS-CoV-2.

'Current and future treatment options for CLL '
Conference Aston, Aston University, Aston St, Birmingham B4 7ET, UK
10.00am to 4.00pm. Enrol from 9.30am
There will also be patient speakers sharing their CLL experience, and time for a Q & A session.
Entry is free, and lunch will be provided.
Look out for the invitation and instructions how to join, and in the meantime save the date!
We look forward to welcoming you.

The results of our CLL Survey

Earlier this year we carried out a survey amongst our members.
The survey was designed to help health care specialists involved in CLL/SLL treatment; to help patients, partners, family and friends to 'live well with CLL', and to inform our lobbying to Government, medical institutions and pharmaceutical companies. You can see the survey findings here:

Survey findings

We want to express our thanks to everyone who replied.

Announcing new developments in our mental health support programme

CLL/SLL is unusual among cancers as diagnosis is so often followed by a period of active monitoring or 'Watch and Wait' (W & W). This can be a particularly difficult time with prolonged uncertainty and fear of what may be to come. Of course, it's not only 'W & W' patients that may need help, but anyone at any point during their CLL/SLL journey.

We therefore launched SupportACT 12 months ago, as a website tool to support the psychological health of people living with CLL/SLL, and their supporters. You can find it here:

https://cllsupport-act.org.uk/

We are pleased to say that it's been a huge success and has helped many people. We want to help even more people and so we are extending SupportAct as follows:

- **Group drop-in sessions**
  Starting in the New Year there will be fortnightly drop-in sessions based on the SupportACT programme. Lasting an hour on Zoom, each is a stand-alone session for up to 20 members:

Thursdays 10.00 – 11.00am starting 5 January 2023 and then first Thursday of each month

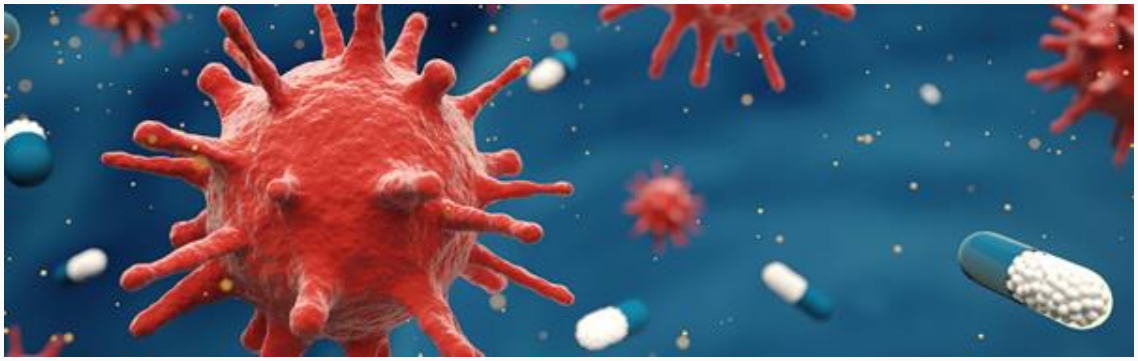
- **One-to-One SupportACT Sessions** Each course will be made up of six weekly Zoom sessions each lasting one hour. Available for patients and their supporters.

The courses will be led by **Therese 'Pinky' Jimenez Agrawal**, who is a foremost occupational therapist who helped to create our wellbeing website Support ACT. She is an Acceptance and Commitment Therapy (ACT) practitioner.

If you think this is for you, please contact membership@cllsupport.org.uk for more information.

We are delighted to be able to offer these opportunities free of charge to members. If, however, you would like to make a donation this will enable us to reach more members.

Covid update - where are we now?



According to the latest ONS survey, Coronavirus (COVID-19) latest insights - Office for National Statistics (ons.gov.uk) COVID-19 infections decreased in England, continued to decrease in Wales and continued to increase in Northern Ireland in the latest week (ending 24 October 2022). The trend was uncertain in Scotland.

The estimated percentage of people living in private households (those not in care homes or other communal establishments) testing positive for COVID-19 was:

- 2.92% in England (1 in 35 people)
- 2.55% in Wales (1 in 40 people)
- 3.34% in Northern Ireland (1 in 30 people)
- 2.69% in Scotland (1 in 35 people)
- Since the end of June 2022, most COVID-19 infections in the UK have been Omicron variants BA.4 or BA.5.

Overall, deaths involving COVID-19 continued to rise in the UK (1 November 2022). However, since the early days of the pandemic there has been a significant reduction in deaths by blood cancer patients suffering from Covid. A recent study has shown that there has been a decrease in fatality rate from 40% to just 4%. This is very good news and is due to improved treatment and to vaccination. Details of the study can be found HERE.

Even so, it's still best to:

- **Make sure you are fully vaccinated**. An Autumn booster jab is now available for people with blood cancer, and this includes members of their family or close associates. This now applies across the UK.
- Avoid crowded places where possible. If you need to be in a crowded area, wear a mask. FFP2, FFP3 and N95 are recommended, although any mask is better than none.
- When meeting friends and relations, think about asking them to test beforehand.

If you catch Covid

If you have Covid symptoms, you should immediately take a **lateral flow or PCR test**. You will need a positive result to be assessed for treatment, which is usually needed within about five days. You can find the procedure to follow on the NHS website **HERE**

Guidance from the NHS, effective from 13 June 2022, for treatment of Covid patients at home is as follows:

• First-line: nirmatrelvir plus ritonavir (antiviral) OR sotrovimab (nMAB), as clinically indicated

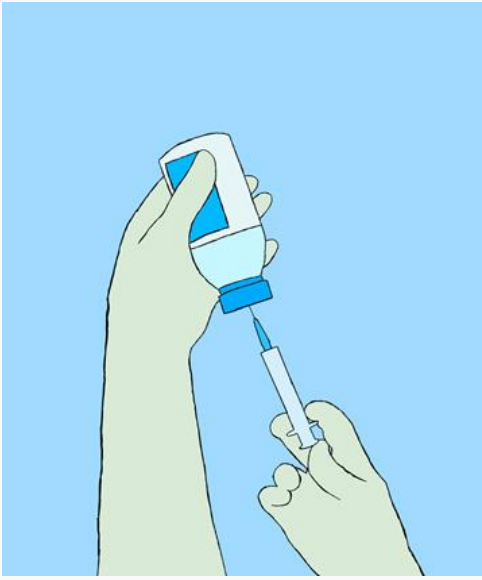
• Second-line: remdesivir (antiviral)

• Third-line: molnupiravir (antiviral)

Note:

- You should be monitored after your first treatment as you may need follow up treatment if your Covid symptoms return, or you continue to test positive.
- Treatment will depend on an assessment of your condition, and you may not receive treatment if you have only a mild dose of Covid-19

FLU Vaccination



Officials at the UK Health Security Agency (HKHSA) have issued a statement stating that they expect that it will be a "difficult winter". They are concerned because the dominant 'flu strain this year is (H3N2) which causes more severe illness.
This makes it even more important that we all get the vaccination as soon as possible. This also applies to close contacts such as family and friends.
To make sure you are fully vaccinated, download our vaccination leaflet here.

Latest news!

New treatment.
Patients on treatment may experience a decline (resistance) in the efficiency of the drug over time. It's encouraging that research and development is still going on to help with this. Pirtobrutinib is a new generation BTK inhibitor showing good results in the Phase 1/2 BRUIN trial in the USA. Further details can be found **HERE**.

HealthUnlocked

Our online forum is 10 years old!
CLL Support launched our world-wide forum for CLL patients, their families and

friends ten years ago this year. From modest beginnings, it's grown to over 10,000 members and is a vital source of reliable information and support for all people with CLL/SLL.
We want to take this opportunity to thank all those who worked so hard to establish the forum in the early days, together with all those dedicated Administrators and Volunteers who have contributed to its amazing success.

Garry Bisshopp
It was with great sadness we learned recently of the death of Garry Bisshopp, who was one of our very early Trustees and for a number of years our chairman. Garry was a passionate advocate on behalf of patients and campaigned tirelessly for better treatments. He represented us on a number of committees and in discussions with government and the NHS.
On behalf of the Trustees, we send our condolences to his family.

Can you help, please?

Please can you share your CLL story?

For those who attended our conferences before the pandemic, an undoubted highlight was one of our members sharing their CLL story. People found it enormously encouraging to hear how others coped with their CLL.

We would like to reintroduce this to webinars and, when we can, face to face, conferences.

Everyone's story is relevant. Do you perhaps have a hobby or job that would help to show how you have managed with CLL? You can do this with a partner, or indeed your partner can tell their tale. Have a look at how other members have told their story:

Sue and Elizabeth's story

If you are happy to share your story for a few minutes, we'd love to hear from you. You would be helping other people with CLL.
Please email: Lewis.Troke@cllsupport.org.uk**.**
Many thanks
Marc Auckland

Fundraising!

Giving Tuesday - Tuesday 29th November

Have you heard about Giving Tuesday?
It takes place this year on Tuesday 29 November 2022.

It's a great way to:

- Volunteer your time,
- Donate money
- Share your skills
- Organise a community event

The list is endless.

Join millions of others from around the globe. Let people know how proud you are of supporting our charity.

Giving Tuesday UK: 29 November 2022

A big thank you for your donations and fundraising to date from all of us at CLL Support Association. You really do make a difference:

£2.50 pays for an information pack
£10 pays for a one-hour call to our helpline
£35 can cover the cost of producing and sending an email bulletin to our members
£50 goes a long way towards paying for a place at one of our conferences.

All donations go directly to covering the costs of the Association.

Cherry Mills cherry.mills@cllsupport.org.uk

Don't forget! Here are two other way you can help:

easyfundraising
feel good shopping

This is another relatively painless way you can help. Nearly all major supermarkets and stores operate this

scheme, which again works by them donating various amounts to your chosen charity for everyday purchases.
Note that our official registered Charity title is: Chronic Lymphocytic Support Association (CLLSA), and you will need to use this title to register. Happy spending!

Amazon Smile is just like the usual Amazon site, same products, same prices. The difference is that if you sign up, CLL Support receives a small percentage of the cost of anything you buy - at no cost to you! It really is that simple! Give it a try!
https://smile.amazon.co.uk

HealthUnlocked

HealthUnlocked is our very active on-line forum, where you will find support and knowledgeable, reliable advice on all things to do with CLL. The site also has a very comprehensive resource of CLL information, which is updated regularly, and is moderated by our team of Administrators and Volunteers. You can check it out here:

HealthUnlocked

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:

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!

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