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## Newsletter

**October 2022 Issue No 09**

Bringing you the latest news and developments in CLL and SLL

**Our free helpline: 0800 977 4369**

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



I trust this finds you well and that you have been able to enjoy the summer months.

Winter is approaching, and as you will see below, Covid infections may be already on the increase, which makes it important to make sure that we all have our Autumn booster vaccination, which is now available. Also, don't forget your annual 'flu jab!

A major announcement in this newsletter is that we will be holding our first conference for over two years later this month in Glasgow. We are very excited that we can, at last, start to put on these very popular events, and we're working very hard behind the scenes to make this a success. Of course, we need people to attend, so, please save the date. I really look forward to meeting some of our Scottish members again, and, of course, those who travel from other parts of the UK.

Thank you to everyone who replied to our call for trustees, and I'm please to report that we have appointed a number of Associate Trustees to help us.

**However, we do still need replacements for trustees who have to step down after their period of service. The areas of responsibility are: Accounts; Information Technology (I.T.); Organising our conferences and webinars, and finally Communications, which includes our website and newsletter.**

These are key areas and we need to fill the places soon. If you feel you may be able to help and would like to join our team, or would like more information, please do let me know at: [marc.auckland@cllsupport.org](mailto:marc.auckland@cllsupport.org).

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

Marc Auckland  
Chair, CLL Support

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**Our first conference for over two years!**



**We are excited to announce that our first conference for over two years will be held in Glasgow on:**

**Tuesday 18 October**

**Voco Grand Central, 99 Gordon Street, Glasgow, G1 3SF.**

**The centre is within the Grand Central Railway complex.**

**'Managing CLL in 2022- Treatment guidelines explained'**

We are privileged to have some excellent speakers and the topics discussed will be very relevant to all people with CLL, and their families and supporters.

**Attendance is free, and lunch and refreshments will be provided.**



**Alison McCaig**  
is Consultant Haematologist at  
Queen Elizabeth University  
Hospital Glasgow.

She will give an overview on the current therapies available for CLL as well as discussing recent developments in first-line treatment, options available at relapse and key factors to consider when choosing treatment.



**Therese Jimenez-Agrawal**

Pinky is a foremost occupational therapist who helped to create our wellbeing website Support ACT. She is an Acceptance and Commitment Therapy (ACT) practitioner and will be speaking about how to come to terms with the diagnosis of CLL.

[Please register your application here](#)

**We look forward to seeing you!**

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## Our latest webinar is now available to view online

In this important webinar, Professor Peter Hillmen and Dr Tal Munir discuss the FLAIR trial and the opening of the STATIC trial for patients on ibrutinib. This development is important for all patients being treated with ibrutinib, as it may have implications for future treatment plans.



**Prof. Peter Hillmen** leads the Experimental Haematology section in The University of Leeds School of Medicine, and the Translational Haematology Research group. He is Professor of Experimental Haematology and Honorary Consultant Haematologist at Leeds Teaching Hospitals NHS Trust.



**Dr Tal Munir** is consultant Haematologist at Leeds NHS Trust, specialising in Chronic Lymphocytic Leukaemia. Dr Munir will be heading the STATIC team.

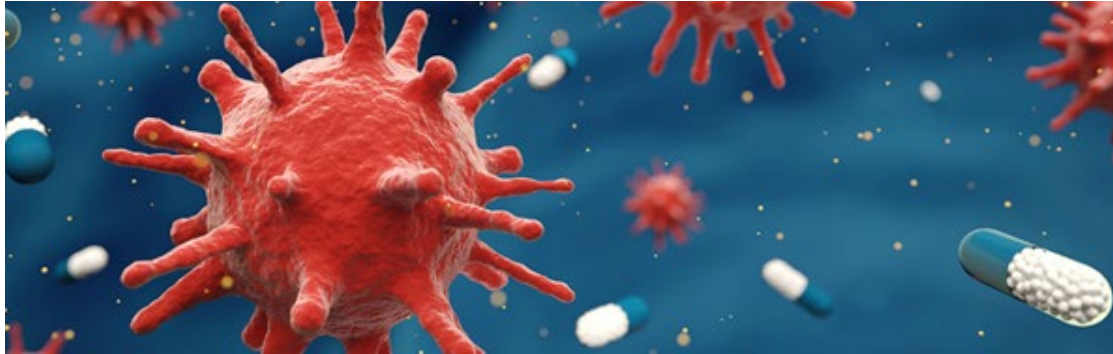
You can read a summary of the FLAIR trial results [here](#)

You can read a summary of the new STATIC trial [here](#)

[Watch the video here](#)

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## Covid update - where are we now?



**According to the latest ONS survey, [Coronavirus \(COVID-19\) latest insights - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/coronavirus/latest-insights) COVID-19 infections increased in England and Wales and decreased in Northern Ireland and Scotland in the latest week (ending 21 September 2022 for England and Wales and 13 September 2022 for Northern Ireland and Scotland).**

This is the first increase seen in England since mid-July 2022 and the first increase seen in Wales since early July 2022. The decrease in Scotland follows an increase in the previous week, which was the first increase seen in a UK country since mid-July 2022.

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

- England 1 in 65 people
- Wales 1 in 50 people
- Northern Ireland 1 in 80 people
- Scotland 1 in 45 people

**These figures may indicate that the next Winter wave of infections is beginning, so we recommend:**

- 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.

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### **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](#)

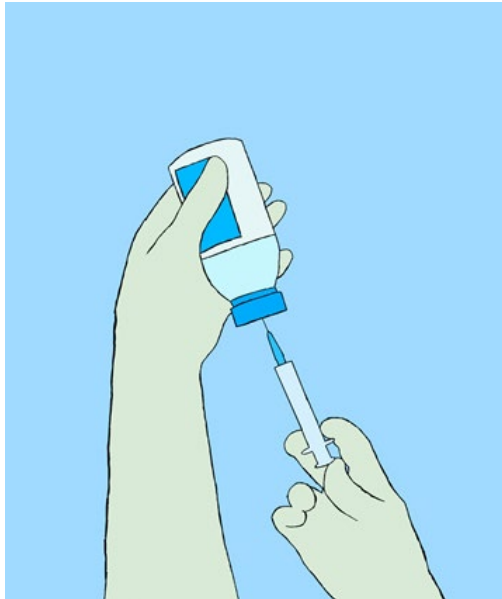
**Guidance from the NHS**, effective from 13 June 2022, for treatment of Covid patients at home is as follows:

- First-line: nirmatrelvir plus ritonavir (antiviral) OR sotrovimab (nMAB), as clinically indicated
- Second-line: remdesivir (antiviral)
- Third-line: molnupiravir (antiviral)

Note that 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.

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## FLU Vaccination



## Officials at the UK Health Security Agency (UKHSA) 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.**

## Latest news!



One of our trustees, Norah, recently appeared on a video for **Cancer52**. She is talking about the emotional difficulties that blood cancer patients have had to contend with during and following Covid. You can watch this short video [here](#). We think you may find it helpful.

## You are invited to help shape cancer research in Sussex....

**Friday 7th October 2.00pm - 4.00pm  
at Brighton and Sussex Medical School.**

The Sussex Cancer Fund invite you to meet their team of blood cancer researchers. The afternoon will start with a tour of the research labs,



followed by a chat over refreshments. It will be a wonderful opportunity to see how the team works and for them to understand what is important to patients and families.

Find out more information and how to reserve your place [here](#).

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### **NURIX clinical trial announced (NX-5948 treatment)**

This trial is recruiting in the following centres:

- The Christie NHS Foundation Trust Manchester, M20 4BX
- Oxford University Hospitals NHS Foundation Trust, Oxford, OX3 7LE
- University Hospitals Plymouth NHS Trust, Plymouth, PL6 8DH
- University Hospital Southampton NHS Foundation Trust, Southampton, SO16 6YD

**The patient groups under this trial are:**

- Group A: CLL or SLL with disease progression after at least 2 prior therapies.
- Group B: CLL or SLL with disease progression after both a BTK inhibitor (BTKi) and BCL-2 inhibitor (may have been individually or in combination).

Full details of this trial can be found [here](#).

Find out about trials, and why you may wish to consider one [here](#).

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**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](mailto:Lewis.Troke@cllsupport.org.uk).

**Many thanks**

**Marc Auckland**

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## **Fundraising!**

**A sincere 'thank you' to all our valued fundraisers. Without your help we couldn't do our work. We know that not everyone can run, cycle, skydive or climb mountains! However, here's a few ways you could help without quite so much strenuous effort.**

**Calling all birthday givers, challenge takers, gardeners and shopping lovers!**

## Could you....

- **Take on a sporting challenge** and raise money for CLL Support
- **Donate your birthday!** Who needs more socks, anyway? Ask people to donate to CLL Support instead of buying you a gift.
- **Shop with a Smile.** If you already use Amazon, sign up with Amazon Smile, and we receive a small percentage of every purchase. It's quite painless!
- **Keen gardener?** Perhaps you're planning to reduce the number of plants that you have, or maybe you have some young plants that you have no room for? How about putting them by your front gate with an honesty pot?

We'd love to hear your ideas, successes - even failures! Let me, Cherry, know at: [cherry.mills@cllsupport.org.uk](mailto:cherry.mills@cllsupport.org.uk)

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## Don't forget! Here's another way you can help:



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!

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## 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](mailto:coordinator@cllsupport.org.uk)

Or download from our website [here](#):

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**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](mailto:membership@cllsupport.org.uk)**

**We look forward to hearing from you!**

