



CLL SUPPORT

Helping people affected by CLL and SLL

Newsletter

November 2021 Issue No.10

Bringing you the latest news and developments in CLL

Welcome to our latest newsletter in which we keep you up to date with CLL matters.



You may be starting to make plans for the Christmas Season, and, after the incredibly difficult events of the last 18 months, coming together to celebrate with friends and family once again feels particularly special. Of course, as CLL patients, we still need to be very careful and remember to take as many precautions against catching Covid-19 as possible. The virus certainly hasn't gone away, and we must remain vigilant.

Although the past 18 months has been very difficult, we've seen so many fantastic examples of how, during adversity, we come together to help those who need support the most. When times are tough, our values of kindness and generosity shine through. The supportive messages on our online forum, [HealthUnlocked](#), are a reminder how important this is.

There have also been very welcome approvals for new treatments in the last year, and, as you will see below, the introduction of new drugs to treat and prevent Covid is very positive news.

As always, we are incredibly grateful for the work of our supporters who have raised money for us in the last year. There have been some amazing efforts, and just one is highlighted in this newsletter. We thank each and every one of you, and without you we couldn't carry on our work supporting CLL patients.

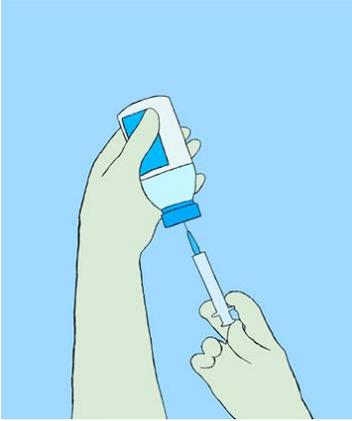
I hope you will enjoy this newsletter and find it informative. As always, we do welcome your feedback and any comments you may have to help us improve it further.

I hope you stay safe and well.

Marc Auckland

Chair of trustees.

3rd dose vaccination confusion



All blood cancer patients are entitled to have a third Covid vaccination as a matter of priority. We are still hearing of patients who are unable to obtain a vaccination, and if you are experiencing difficulty, we have set out [here](#) what you can do to try to get your third dose. If you are still waiting, please contact your medical team for help.

We believe that it's vital for CLL patients to have the third jab as some cover against Covid is better than none.

While we're talking about vaccinations, this is a gentle reminder that, if you haven't already done so, it's **now time to have your 'flu vaccination**. Flu is expected to be more severe this Winter as it almost disappeared last Winter because of the lockdown. We've heard that supplies are short in some areas, so please contact your GP if you are still waiting to be called.

Good news for all CLL patients!



The first pill designed to treat symptomatic Covid has been approved by the UK medicines regulator.

The tablet - **molnupiravir** - will be given twice a day to vulnerable patients recently diagnosed with the disease.

The UK is now the first country in the world to approve an antiviral that can be taken at home for Covid.

Molnupiravir, developed by the US drug company Merck (known as MSD in the UK), is the first dedicated oral antiviral medication for Covid. You can find more information [here](#).

In other news:

**** Pfizer has announced a new antiviral pill** that it says could reduce the risk of hospital admission and death from Covid-19 for the most vulnerable by up to 90%. Although it is not licenced in the UK at present, the government has ordered 250,000

courses of the drug, **paxlovid**, which is expected to be available early next year.

And:

**** AstraZeneca** has published results of the **Provent phase 3 trial** for what it claims is the first long-acting antibody combination to prevent Covid-19. The trial showed a "**77% reduced risk of developing symptomatic COVID-19.**" The drug is designed to prevent Covid-19, rather than treat it after infection. You can find full details [here](#).

Together with molnupiravir, these treatments could herald a significant change in the way in which Covid is treated in the vulnerable.

This news is in addition to the Covid treatment, **Ronapreve**, we mentioned in the last newsletter. Hospitals are now building a variety of treatments for Covid-19, which is encouraging news.

News about our next webinar!

The topic will be: 'CLL, exercise and nutrition'
Put the date in your diary:

Tuesday 16th November. 13:00 pm-14:30 pm
Join from 12.45 pm. We will close at 2.30 pm

The keynote talk will be given by Dr David Bartlett



Dr Bartlett is Lecturer of Exercise Immunology at the University of Surrey and Adjunct Assistant Professor of Medicine at the Duke Cancer Institute in North Carolina. He is an immunologist focused on manipulating exercise and diet to enhance immune functions, overall health, and disease prognosis in adults with chronic diseases such as CLL.

Recently, we put out a call for candidates who would be prepared to join a study investigating how exercise and nutrition can affect the progress and impact of CLL in patients. There has been tremendous interest, and in this webinar, Dr Bartlett will be explaining more about the research he is undertaking and what he is asking of volunteers.

Dr Bartlett will be joined by a patient speaker and other expert speakers to help us understand the study, what would be expected of participants, and how to join.

Panel Members will be:

David Bartlett – Lecturer of Exercise Immunology
Ralph Manders – Lecturer of Exercise Physiology
Barbara Fielding – Reader in Nutritional Sciences
Long Li – Oncology Dietitian
Caitlin Jeary – Oncology Dietitian

Leading the panel discussion will be **Dr. Renata Walewska**, Consultant Haematologist at the **Royal Bournemouth Hospital** and Chair of the UK CLL Forum.

There will be a Q & A session and you can submit your questions in advance or on the day.

Exercise and nutrition are important topics for CLL patients and we anticipate a high demand for places, so

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

We look forward to welcoming you!

Our new trustee



We are very pleased to welcome Dr Ben Kennedy, who has agreed to become our latest Trustee recruit. As many of you will know, Dr Kennedy is Consultant Haematologist at the **Leicester Royal Infirmary**, and has spoken at many of our conferences and webinars. Dr Kennedy will be advising us on all medical matters and his input will be highly valued by trustees and CLL Support members alike. We look forward to working with him.

Can you help?

We also have a key vacancy for an **Associate Trustee**, so if you think you may be able to help, please contact marc.auckland@cllsupport.org.uk. Associate Trustees offer us expert advice and usually need to devote just a few hours a month. We are currently interested in talking to anyone with good I.T. experience, particularly in website management. They will work with and assist our current trustee lead in this important area.



From time to time we feature our various charity partners and today we are highlighting the work of the UK CLL Forum.

The UK CLL Forum is the body which represents CLL doctors in the UK, and CLL Support is their charity partner. The Forum's mission is:

- The advancement of education of the general public, in particular in the treatment of those suffering from CLL and related disorders.
- Development and provision of policy guidelines for such treatment.
- Promotion of communications and exchange of information between research groups and healthcare professionals.

The UK CLL Forum website has a lot of information intended for patients and clinicians alike, and it gives a comprehensive view of their work. You can find it [here](#).

Great fundraising feat!

Our congratulations and heartfelt thanks for this month's star fundraiser go to Anita Simpson.

Anita is planning to walk across the Jordan desert to raise funds for CLL Support! She will be walking from the Dead Sea to the ancient hidden city of Petra and has a target of £1000.00. Anita expects to start her massive trek when Covid restrictions are lifted next year. You can find out a lot more about why she is tackling this adventure on her JustGiving page [here](#). Please have a look and support this brave effort! We wish Anita well in her adventure and we'll let you know how she gets on.



If you have been involved in fundraising, or have any ideas for fundraising, we'd love to hear from you. We do rely on our fundraisers to help us carry on our work. You can always contact us at: membership@cslsupport.org.uk

Another great fundraising opportunity!



One of the most sought after cycling events of the year is the 'Ride London' challenge.

Entry tickets for the event are very difficult to come by and we are very pleased to have managed to obtain just FIVE. We will be making these available on a first-come-first-served basis. So, if you or someone you know is interested in this 100 mile event, contact us as soon as you can. You can check out some of the details [here](#).

Please note the entry conditions:

- Tickets are **FREE** (usual charity entry price £189.00), but to cover the cost we ask for a minimum fundraising of £350.00 per entry. More would be great!
- All fundraising will be by individual JustGiving pages.

For your entry ticket to this great event, contact us at membership@cslsupport.org.uk

Remember - it's first come first served! So get your request in now, and start contacting your sponsors!

Don't forget!

There are less strenuous ways to 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. Why not give it a go - it won't cost you anything!



We support the letter to the government from One Cancer Voice



As part of our on-going cooperation with other charities, we have joined together with 49 other cancer charities to call for clarity on NHS workforce funding in the Annual Spending review. The letter from One Cancer Voice was sent to the Chancellor of the Exchequer and Secretary of State for Health and Social Care.

You can find the full letter [here](#)



World Mental Health Awareness Day

October saw World Mental Health Awareness Day take place on the 10th of October, but we should continue to look after our mental health all year round. We've put together a new resource, Support Act, designed to help you prioritise your mental health. Have a look here:

[CLL Support Act](#)

A snippet of a social media post for CLL Support. It features a large purple circle with a white center and a smaller teal circle. Below the circles is the CLL Support logo, which consists of three overlapping circles in purple, teal, and pink. To the right of the logo, the text reads "CLL Support" and "18,392 members • 30,492 posts". Further right, there is a "Write" button with a pencil icon and a checkmark icon.

Sharing information, empathy, support, education, advice & empowerment with those affected by Chronic Lymphocytic Leukaemia (CLL/SLL)

CLL SUPPORT
CLL Support
18,392 members • 30,492 posts

Write

Have you tried our online forum Health Unlocked? It's the largest forum in the world devoted to CLL and It's full of good advice and information about CLL. You will always be sure of a warm welcome.

[Check it out here](#)

Shingrix vaccine now available for 70 to 79 year olds!

It has been announced that the Shingrix vaccine against shingles is available for everyone aged between 70 and 79.

Shingrix has also been licensed in the UK for the prevention of shingles in adults aged 50 years and older, as well as in adults 18 years of age or older who are at increased risk of shingles. However, these groups will have to pay for the vaccine, as for them it's not available on prescription.

Shingles is of real concern for CLL patients because of our compromised immune system, which means that the virus can be more severe and difficult to control.

The standard vaccine should not be given to CLL patients, as it is a live vaccine and can cause severe complications.

You can find more information on shingles and how to recognise it [here](#):

Shingles



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. Contact us at: coordinator@cllsupport.org.uk

We look forward to hearing from you!.