



CLL SUPPORT

Helping people affected by CLL and SLL

Newsletter

October 2021 Issue No.9

Bringing you the latest news and developments in CLL

Video of our latest webinar now available



In a stimulating talk, **Dr. Alison McCaig**, consultant haematologist at the Queen Elizabeth University Hospital, Glasgow, spoke about "**Living with CLL**" from a Scottish perspective but of interest to CLL patients everywhere.

There were also very entertaining stories from CLL patients and an update on the **Anchor Centre** at the Aberdeen Royal Infirmary by Louise Budge.

The video and slides used in the presentation can be found [here](#)



Third Covid vaccination for CLL patients. Important information.

What should you do if you have CLL and can't get a third Covid vaccine dose?

With many people reporting issues with the rollout of third doses of the vaccine, we've set out [here](#) what you can do right now to try to get your third dose if you have not already been invited for it.

NHS antibody survey

We've received a large number of complaints from members about this survey. People have had a variety of problems including not being able to finish the survey, survey 'freezing' part way through, and receiving a report that they have antibodies, but the number has not been disclosed.

The survey was plagued with technical problems at the beginning, but these, mostly, seem to have been resolved. If you have tried to register but haven't been able to get through, you might like to give it another go [here](#).

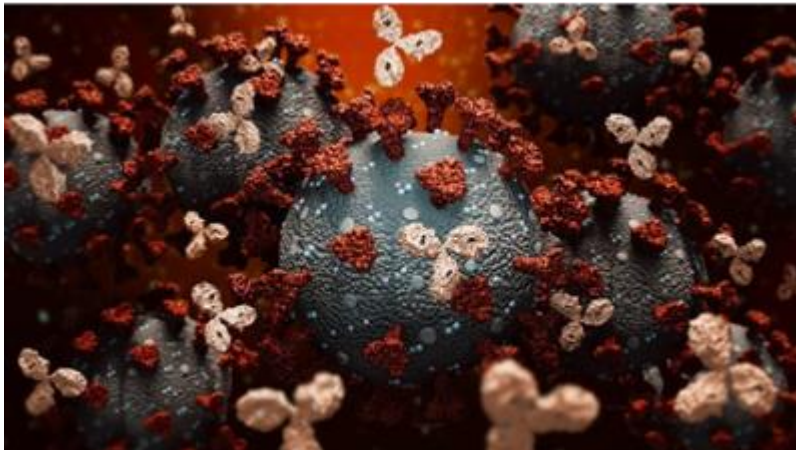
However, a word of caution: a recent addition to the survey site says: *"It is currently not clear what antibody levels are helpful and protective against future COVID-19 infection. This means that at an individual level, there is currently uncertainty about the exact meaning of the results."*

For this reason, the number of antibodies will not be given to each person, just whether there are any antibodies at all.

This may be disappointing, but you will still be helping in important research.

Until we can understand what antibody levels for CLL patients really mean,

we recommend that you continue to take all necessary precautions such as mask wearing, social distancing and hand washing.



New drug Ronapreve for Covid patients announced.

Earlier this month we announced that this new treatment had been given approval for use under certain circumstances. **You can read our full report [here](#).**

We believe this is very good news indeed for CLL and other blood cancer patients. However, some concern has been raised by one of the conditions for administering the drug:

- **immune compromised: no detectable antibody to Covid-19, and inpatient admission for Covid.**

The key point here is the need for no 'detectable antibody.' Some members have reported having a test which has showed some, undefined, antibody level and are concerned that this may preclude them from Ronapreve treatment if required.

This should certainly not be the case. The Conditional Authorisation

notification issued by the pharmaceutical company, Roche, states:

"This authorisation does not preclude an authorised prescriber supplying or administering the product to a patient for whom it is not recommended in accordance with the instructions for use, or otherwise than in accordance with the instructions for use, in circumstances where that authorised prescriber is directly responsible for that patient and the supply or administration of the product is to fulfil the special needs of the patient where, in the professional judgement of that authorised prescriber, the welfare of the patient is likely to be in jeopardy unless the product is administered." (Our emphasis). We hope this will reassure those patients who may be affected.



CLL Support has joined together with 49 other cancer charities, as part of One Cancer Voice, to send a united message to all governments across the UK: we stand ready to work with you to help plot a route out of the pandemic, and towards world leading cancer services.

Our letter has been sent to [Boris Johnson](#), Chancellor [Rishi Sunak](#) and Health Secretary [Sajid Javid](#). The letter was given full coverage in [The Daily Mail](#)

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



Support Act Launched

Last month we launched our new website **Support ACT**.

This is a major development in our determination to help reduce the stress of CLL for patients and their families. Check it out [here](#).

Fundraising feat!



Our congratulations and heartfelt thanks for this month's star fundraiser go to Natalie Smith.

Natalie completed a 10k "tough mudder" challenge and has raised **over £1300** for CLL Support. She says it was a great day, and that her heart rate went up to 188bpm after one of the challenges !! Brilliant effort!! With Natalie in this amazing effort were Amber Thompson, Connor White and James Larsson. Our thanks to them all. Natalie's fundraising page with the story behind this challenge can be found [here](#). Check it out, and help raise the total even higher!

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!



Shingrix vaccine now available for 70 to 79 year olds!

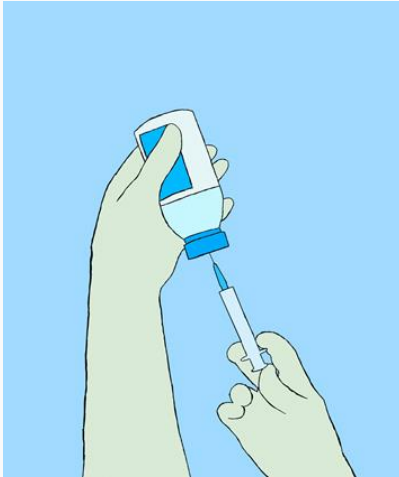
It has been announced that the Shingrix vaccine against shingles is available for everyone aged between 70 and 79.

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](#).



While we are 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.



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!
