



Newsletter

September 2021 Issue

No.8

Bringing you the latest news and developments in CLL



Hello, and welcome to our latest newsletter. I hope you will find it interesting. It gives you an idea of the breadth of our work, thanks to your support and generosity.

It's an extremely busy time for us, with representations to various authorities about, amongst other things, Covid-19 vaccinations for the immunocompromised. We work closely with other charities to make our voices heard on behalf of patients, and we will continue to do so.

I am always amazed at the efforts of our supporters to raise funds, from the skydiving in our last newsletter to the one from Natalie Smith and her friends which we feature below. Thank you to everyone. We really appreciate your efforts. If all this is too strenuous, please have a look at our 'Easy Fundraising' section below. It's a painless way of helping us to help you.

I want to assure you that we are still here for you in these difficult times, especially if you have concerns about the impact of Covid-19, or questions around vaccines. You will find answers to many queries on our website, including the third vaccine, [here](#). We continue to update our website as new information emerges, and our free helpline is always available: 0800 977 4396.

Most of all, on behalf of all trustees, I wish you good health and hope that you will remain safe.

Marc Auckland
Chair of trustees

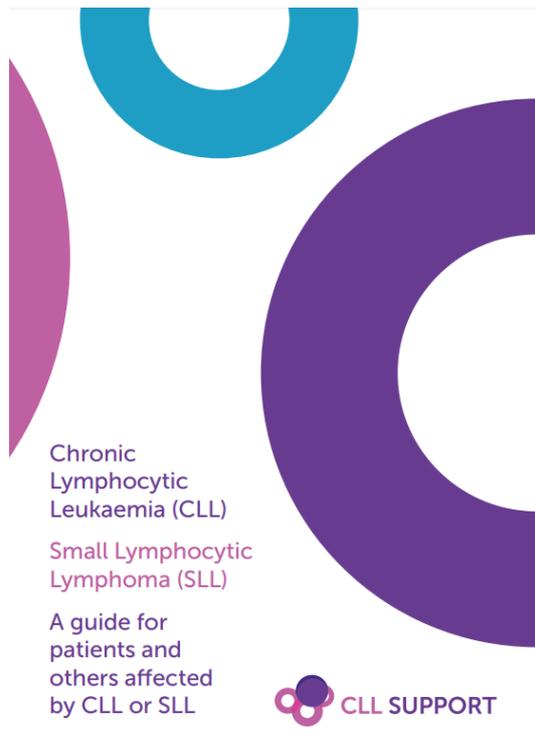
World CLL Day 1st September 2021



As part of our contribution to World CLL Day, part of Blood Cancer Awareness 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](#).

Our new booklet



We've updated our popular booklet, containing the latest information and advice on CLL. It's being sent to all members.

If you have not received yours or would like additional copies you can order from the website [here](#)

Please also consider taking a few extra copies to give to your clinic on your next visit, so that other patients may benefit.

Thank you!



Our sister charity, Blood Cancer UK has also just published a booklet for recently diagnosed patients. Although not exclusively for CLL patients, it does contain good advice. You can find it [here](#).



Third Covid-19 jab go-ahead for blood cancer patients.

The UK government has announced that severely immunosuppressed adults and children aged 12+ should have priority getting a third Covid vaccine dose. **This is different from the national booster programme and has caused some confusion** For an explanation of the difference, please see [here](#).

A third jab is crucial to protect those at the highest risk of illness and death from coronavirus, irrespective of age. GPs and hospital teams have been asked to identify these patients and arrange third doses. See this letter to all GPs and vaccination centres in England [here](#).

We have heard of cases where CLL patients have been told that they do not qualify for this third jab. The Green Book, which specifies to doctors what treatments should be given to patients, lists conditions that constitute severe immunosuppression, **including blood cancers, even when no active treatment is being given.**

In our view, it is clear that all CLL patients should be offered a third vaccination as a matter of priority. You may wish to use the information above if you are refused a vaccination for any reason.



We are very pleased that a paper based on the surveys conducted by Leukaemia Care, UK CLL Forum and CLL Support throughout the COVID pandemic has been selected for this prestigious conference. This was a major piece of research which identified areas of concern for CLL patients and enabled clinicians to adapt accordingly. Key parts of the research will be presented by **Dr Renata Walewska**.

Other contributors were: Prof. Greg Fegan, Swansea University; Prof. Christopher Fegan, Cardiff University; Nick York, Leukaemia Care; Brian Gardom, trustee, CLL Support Association; Marc Auckland, Chair of Trustees, CLL Support Association; Nicole Scully, Leukaemia Care.

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](#).



Our popular webinars are back!

The keynote talk will be:

Living with CLL; a Scottish perspective with Dr. Alison McCaig, consultant haematologist at the Queen Elizabeth University Hospital, Glasgow

After a short Summer break, the first webinar in our next series will be on

29 September at 1.00 pm.

Although based in Scotland, this webinar will have information relevant to all CLL patients in the UK.

There will also be a talk by **Martin Hannah**, a Clinical Nurse Practitioner, and two patients will speak about their own CLL experiences. **Louise Budge** will give an overview of the new **Anchor Centre at the Aberdeen Royal Infirmary**

There will be plenty of time for questions.

Reserve your place now by emailing: webinars@cllsupport.org

Fundraising



We love to mention as many of our fundraisers as possible, and this time we're featuring **Natalie Smith**.

Natalie, and a few brave friends, are going to be hurling themselves through mud, ice and electric currents in the **Tough Mudder 10k in October 2021!!** Natalie's mother was diagnosed with CLL in 2017 and is currently in treatment.

Natalie and her friends have so far raised an amazing £900 towards their target of £1000. You can help them reach their target by supporting them and us on their JustGiving page [here](#)

We wish Natalie and her team well and thank them for their efforts!

If you are raising funds on our behalf, please do let us know and we'll mention you here.



Fundraising doesn't have to be quite so strenuous if that's not your style!

Here's a much easier and less painful way:

We are now registered with **Easy Fundraising**, a charity set up to help other charities to raise funds on almost any purchase made online.

How it works:

- You register with Easy Fundraising [here](#)
- Easy Fundraising has literally hundreds of companies giving their support, including all the major supermarkets and most large retailers.
- Each time you buy something from these retailers Easy Fundraising will allocate a small percentage to CLL Support - at absolutely no extra cost to you, and it's totally automatic!. It's that easy! And it helps us enormously.

Why not give it a go?

More from World CLL Day

We had a wonderful - and creative - response to our request for pictures of 'umbrellas' in support of the theme of **World CLL Day**. Here are just a few of them. We'll be putting more up on our website. Just love the one with the dog!

Thank you to everyone who took part.



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!

