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Newsletter

December 2023

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



Seasonal greetings to you all! Since I last wrote to you, we have had a very successful London Conference

Numbers attending were good, both in person and on Zoom. If you missed the event, you can read about it in the newsletter and also watch the key presentations in the videos available on our website. We are so pleased that we can bring the latest developments in the CLL world to so many of you.

I am also very proud of how we are able to represent the interests of the CLL

Community with others who are able to influence developments to our benefit. Recently this has included making submissions to NICE about potential new treatments, attending events run by the UK CLL Forum where we meet with the scientists and clinicians involved in current developments in the CLL field and presenting at the Clinical Nurse Specialists CLL Study Day. Wherever I have been and whoever I have met, I have been overwhelmed by how highly others view CLL Support.

In October the Trustees agreed our programme of activities for the next year. If you would like to read more about our plans you can do so [here](#). I hope

you will agree that our Trustees and Associates, ably supported by our part-time staff team of Sarah and Cherry, do a fantastic job for you. We need funding and volunteers to make all this happen. If you are able to contribute to our Christmas appeal, we would be very grateful. And do please get in touch with me if you might be interested in giving some of your time to help with our activities. As with any charity, we need a constant flow of new Trustees. At the moment we are particularly keen to find someone who could liaise with our developers on the website. Please make my Christmas by getting in touch!!

With my very best wishes.

Hilary Lindsay

Chair, CLL Support

hilary.lindsay@cllsupport.org.uk

HEALTH MATTERS

NICE have approved Zanubrutinib/Brukinsa for the treatment of UK CLL patients - [click here to read the full report](#)



A reminder that during the autumn and winter, you may need to get vitamin D from your diet because the sun is not strong enough for the body to make vitamin D.

But since it's difficult for people to get enough vitamin D from food alone, you should consider taking a daily supplement containing 10 micrograms (400 IU) of vitamin D during the autumn and winter. The full NHS guidance can be found [here](#)

IMPORTANT UPDATE ON LATERAL FLOW TESTS

The latest information on obtaining LFTs

- **England** : <https://www.nhs.uk/conditions/covid-19/treatments-for-covid-19/> LFT's are no longer sent out by mail, and have to be collected from a local pharmacy.
- **Scotland**: you can still order kits here: https://nhsscot.service-now.com/covid_lateral_flow_test_order_results
- **Wales**: you can order tests online for home delivery (on [GOV.UK](https://www.gov.uk)) or by calling 119 <https://www.gov.wales/get-tested-coronavirus-covid-19#102413>
- **Northern Ireland**: Free lateral flow tests are no longer available to order online. You can collect them from a local pharmacy. <https://www.nidirect.gov.uk/articles/coronavirus-covid-19-testing-and-stay-home-advice>



The London conference on the 26th October was a huge hit. Dr Samir Agrawal's talk in the morning, along with the patient story, was hopeful and warm. He spoke of the welcomed progress toward a more patient focused practice, which is key for us now that there is choice in treatment for people with CLL.

There was plenty of time for questions. The afternoon session was led by Pinky Jimenez who actively helped us get a different perspective on how to carry the stresses of CLL using ACT, Acceptance and Commitment Therapy.

An interview with a member who has benefited from CLL Support ACT was enlightening. Then another talk by Dr Tim Barrow on the research being done on CLL left us confident in the continued work being done to understand and treat CLL. Most of the conference is available on line at <https://cllsupport.org.uk/news-events/conference-reports/>

11 Cavendish Square was centrally located and accessible, had a lovely room for us with excellent AV equipment, and a sunny orangery for lunch.

We hope you can join us in London next September as we recognise our 20th anniversary as a charity supporting individuals and families affected by CLL.

Norah Grant
Trustee

We asked, You said, We did

We had our usual and much appreciated round table discussions at the London conference. Again we asked you for your tips and hints that you would like to share with others. There are no big surprises in what people said, but nevertheless they provide useful reminders for us all:

- Empower yourself through knowledge (there's loads on [our website](#)) – and then just keep asking questions.
- Look after yourself mentally as you come to terms with your diagnosis – it will help to improve your outlook. If you haven't done so already [have a look](#) at our special Support ACT resource designed especially for people affected by CLL.
- If you need treatment and there is a clinical trial available, consider signing up for it. To read more about clinical trials scroll down on our [treatment page](#).
- Take some form of exercise or relaxation – whatever works best for you.
- Last but not least, try to get enough good quality sleep.

Thank you so much to the delegates for sharing your suggestions.

WEBINAR - 11TH DECEMBER 2023

'The benefits of exercise and the science behind it'

We are hosting a two part webinar with Dr David Bartlett from the University of Surrey.

Morning Session 10:30 - 12:00

Dr Barlett and Ellie Mills presentation followed by Q&A

[ZOOM LINK HERE](#)

Passcode 707185

Afternoon session 2:30-3:30

'CLL Support Members - Catch up and Chat'

[ZOOM LINK HERE](#)

Passcode 227376

IT'S THAT TIME OF YEAR AGAIN!

The shops are starting to get busy and lots of us will be shopping online this year to keep away from the crowds. How about helping CLL Support while doing your Christmas shopping from the comfort of your own home, and it is FREE as well.

All you have to do is remember to use easyfundraising. Over 7,500 brands will donate to Chronic Lymphocytic Leukaemia Support Association UK .



These donations really help us and all you have to do is use easyfundraising when you're ordering the things you'll be buying anyway.

[CLICK HERE FOR MORE DETAILS.....](#)

PATIENT STORY - Marc Auckland

Our Former Chair, Marc Auckland was recently featured in an edition of Leukaemia Cares newsletter and they have kindly agreed that we can reproduce it [here](#) for CLL Support Members.

Vote for CLL Support!



For 12 days in December, Movement for Good will be drawing 10 charities each weekday between December 1st and 18th to each receive £1,000. The deadline for the last draw is **17th December 2023**. With your help, CLL Support could be one of the 10 charities this year. Please nominate us by clicking on the link below.

[Vote Here!](#)

AbbVie - My CLL Life

Approaching treatment can be a very stressful time with lots of decisions to be made. One of our trustees, Debbie recently recommended a useful guide which has been produced by AbbVie while supporting CLL Support members

'I recently shared the MyCLLlife preparing for treatment discussions guide in our WhatsApp Under 60s group. A member was concerned that treatment had been suggested to them. They had another appointment arranged to discuss this at which they were hoping to postpone treatment. They found the guide extremely helpful, as did several other members of the group with some commenting that they wished the guide had been available earlier when they had faced treatment discussions.'

[You can find the guide here](#)

FUNDRAISING UPDATE



Rachael Windsor took part in the 2023 London Winter Walk. Rachael and her cousin Leah have decided to walk the full 26 miles in January 2024. They are hoping to raise money for CLL Support as Rachael's dad, uncle and friend's husband all have CLL.

Link to Rachael's Just Giving page [here](#) On behalf of the members and Trustees of CLL Support, thank you Rachael for supporting our Charity.

Ben Panesar is a member of CLL Support who was diagnosed with CLL in 2014. Ben is a hotelier from Balsall Common. As a keen runner, Ben usually runs over 200K a month in his spare time and wants to get fit for his sons wedding in January.

On 17th September Ben took part in the fun run and raised an amazing £2,620 for CLL Support! Lets all wish Ben a massive well done on his fundraising and thank him for his support.



CLL Support Christmas Donations Campaign 2023

Our annual Christmas Donations Campaign was launched on 14th November this year. Our aim this year is to increase our membership and raise funds, especially regular donations to help us plan longer-term and ensure we can support as many people with CLL/SLL and their families/supporters as possible in the months and years to come.

- Membership numbers have increased from 3,456 to 3471 since the start of the campaign
- Donations at the time of writing were £1,129. Thank you so much to those of you who have donated so far. You really are making a difference.

Don't forget to let us know about any fundraising you are doing as we would love to share your stories (and photo's) with our members.

This Campaign will be running until the end of December. Final results will be in our Spring Newsletter. If you would like to donate, go to our website [here](#) or Just Giving page link is below.

[CLL Support Christmas Campaign 2023 - JustGiving](#)

A huge thankyou to everyone who contributed to our Summer Campaign 2023. It really is appreciated. We raised just over £7K.



Bourne to Sing - Community Choir

Kerry Evenden is the Musical Director for a community choir called 'Bourne to Sing' who are based in Eastbourne. They perform 4-5 events every year to raise money for charities. This year 'Bourne to Sing' have chosen to fundraise for CLL Support as it is a Charity close to Kerry's heart. Kerry is currently in remission from CLL.



'Bourne to Sing' are having two fundraising concerts for CLL They will also be performing at other. Carol singing events.

We're hoping to have some photo's for our Spring newsletter along with the results of Kerry and 'Bourne to Sing's fundraising this Christmas.

All of us at CLL Support would like to wish Kerry and her choir "Good luck" for the 10th December.

Wizz Air Hackney Half 2024 – Sunday 19th May 2024

Another event for those keen runners among you. The fantastic route showcases the historic Broadway Market and vibrant street art of East London. With live bands and entertainment throughout the course, this isn't just a race, it's a full-on festival. Sounds like a great event.

[Let's Do This — What will you do next? \(letsdothis.com\)](https://letsdothis.com)

For more information regarding fundraising – maybe you are taking on your own challenge and would like to raise some money in the process – please contact cherry.mills@cllsupport.org.uk



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!