



Newsletter

October 2024 - Issue No 05
Our free helpline: 0800 977 4396

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



Message from the Chair

I hope the summer enabled you to get out, despite the weather. Already it is autumn! Keats may have called it the 'season of mists and mellow fruitfulness' but for me it seems to be the season of vaccinations. I've just been asked to book my COVID and 'Flu jabs and have been contacted about the new RSV jab as I am in the 75-79 age range. Please do read the article in the newsletter about reviewing your vaccines. Having the vaccines appropriate for you and trying to avoid infections are just so important for the CLL and SLL communities.

On September 24th we held our twentieth anniversary conference in London – with record numbers attending in person and on Zoom. What a milestone! It was just so good to be able to celebrate the development and success of CLL Support over the last twenty years alongside the development and success of treatments for CLL and SLL. Both have done very well! You can read more about the conference in the newsletter.

One of the highlights of the day was to hear all the amazing achievements relating to Challenge 20. This initiative was partly about making us all feel good and partly about raising money. The contributions from those present at the conference enabled us to reach our £20,000 target – with an additional bonus of several thousand pounds from Gift Aid. A fantastic result! Thank you all so much. We'll be sending round a full report about Challenge 20 this month.

With my very best wishes.

Hilary Lindsay

Chair, CLL Support

hilary.lindsay@cllsupport.org.uk

Medical Matters - Seasonal Advice

With winter approaching, it's important to review your vaccinations, and make sure you are up to date. Here are some of the key ones:

- **Covid.** The Autumn vaccination round will commence soon. You should be contacted by your GP or the NHS for an appointment. Research has shown that regular vaccination progressively helps to minimise Covid attacks, and we strongly recommend having the vaccine.
- **Flu vaccine.** The Autumn flu vaccine will become available from 3 October, and, again, you should be notified by your GP, or the NHS.
- **RSV.** (Respiratory Syncytial Virus). RSV is a common cause of coughs and colds. It usually gets better by itself, but it can be serious for older adults, particularly those with a weakened immune system. This is a new vaccination, currently for people aged 75 to 79, and will be available from 1 September 2024. You should be contacted by your GP for this.
- **Shingles.** This is a viral infection that causes a painful rash. Shingles is of real concern for people with CLL because of the weakened immune system, which means that the virus can be more severe and difficult to control. The only vaccination available for people with CLL is Shingrix, which is a non-live vaccine. You must not have a live vaccine. If you have not already had this vaccination, we would urge you to do so. Check with your GP.
- **Pneumonia.** For pneumococcus, modern practice for CLL patients when diagnosed is to give two vaccines. These are known as Prevnar 13® or 15 (child vaccine) which should be given at least 2 months before Pneumovax 23. You should talk to your CLL consultant about having these. Your G.P. may not be aware of this. It's not necessary to have these vaccinations annually, but it's worth checking with your GP to make sure you are up to date.

People with CLL are more prone to infection because of a reduced immune system. Infections can be longer lasting, and more harmful. We urge you to make sure you are fully up to date with all the available vaccinations.

You may wish to have a look at our vaccination leaflet, which you can download, [here](#).

Finally, from October we suggest you think about taking a **Vitamin D supplement**, as levels tend to decline during the winter months. If you choose to take vitamin D supplements, 10 micrograms a day (400 IU) will be enough for most people.

Always check with your medical team before taking supplements.

Report on our London Conference

As our Chair, Hilary Lindsay says in her foreword, our 20th Anniversary Conference, held on 24th September at the King's Fund building in London's Cavendish Square, was an amazing event. It was just so good to be able to celebrate the development and success of CLL Support over the last twenty years alongside the development and success of treatments for CLL and SLL. An absolute win:win. The day had so many highlights. In fact the only lowlight was the weather that made travel challenging for quite a few of us. Despite this one hundred were there in person with another 70 joining on Zoom.



Highlights included:

- A review by our Chair of 20 significant achievements of CLL Support over the last 20 years
- A fantastic poster display featuring in more detail many of our achievements and the people who had made them happen.
- A very moving patient story from Trustee Anthea Holland
- A tour de force presentation by Professor George Follows on 'CLL and the Current Landscape' followed by a lively question and answer session
- A delicious lunch with lots of time for delegates to chat
- A heartwarming presentation by Trustee Debbie Yates of all the successes achieved during our Challenge 20 initiative, culminating in Vice Chair John Greensmyth's cycle ride from Lands End to John O' Groats and David Warner's 1,196 mile walk in the opposite direction. These days CLL treatments seem to have the same effect as eating a lot of Popeye's spinach.
- A second compelling presentation, this time by Dr Piers Patten on 'CLL Treatments; Past, Present and Future' followed by a panel discussion where Dr Patten was joined by Dr Ben Kennedy, Pinky Jimenez-Agrawal and Trustee Peter Allen and ably facilitated, as indeed was the whole Conference, by Vice Chair John.
- A refreshment break where everyone was served a cake embossed with our 20th Anniversary logo.
- Round table discussions where delegates were able to share their experiences and as ever benefit so much from each other's support. Many of the comments reinforced Molly Wilkinson's top tip shared as

part of Challenge 20 which was to 'find what makes you happy and ringence it'.

Videos of the presentations will be going on the website when they are available as will the posters so anyone will be able to access all these resources.

Our next Conference is in Edinburgh on Thursday 7th November. The first one of our next twenty years!



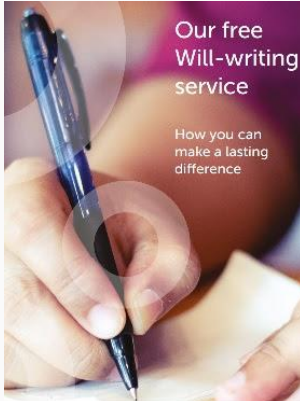
Our Next Conference is being held in Edinburgh on the 7th November 2024. Full details are being sent out to members this week and you can book a place here!

[Book Now!](#)

If you missed our York conference, you can find the videos here:

[Click here for York conference videos](#)

Legacy Giving



CLL Support is currently a member of The National Free Wills Network which gives us the opportunity to offer a limited number of valid 'simple' Wills entirely free of charge. We completely understand that writing a will is a sensitive matter but it really is the best way to ensure that your final wishes are carried out and that your loved ones don't endure additional stress. Of course it would be wonderful if you choose to remember our Charity in your will but you are under no obligation whatsoever to do so.

If you are interested in finding out more, please email cherry.mills@cclsupport.org.uk to request a referral pack.

Autumn/Winter Support ACT drop-in Sessions



Support ACT (Acceptance, Commitment Therapy)
<https://cclsupport-act.org.uk/>

We are very pleased to announce the dates for Round 4 of Support ACT which will take place each month October 2024 – March 2025:

Session	Topic	Thursday mornings 10am	Tuesday evenings 7 pm
1	Introduction to ACT – developing psychological flexibility	3 rd October	15 th October
2	Acceptance	14 th November	19 th November
3	Breaking the power of your thoughts	5 th December	10 th December
4	Being present	2 nd January	21 st January
5	A meaningful life – reconnecting with my values	6 th February	18 th February
6	Doing what matters	6 th March	18 th March

If you haven't already tried Support ACT, please have a look at our website: <https://cllsupport-act.org.uk/> and if you feel it's something that you would benefit from, please get in touch.

If you would like to apply to join one or more of the sessions, please send your name, email, mobile number and date of birth to Cherry Mills: cherry.mills@cllsupport.org.uk. If more than one member of your household would like to attend, please provide details for each applicant. Priority will be given to new applicants and those who have missed sessions in previous rounds. If we receive more applicants than there are places, we will operate a waiting list.

We look forward to welcoming you to one, or more, of our Zoom sessions. We also have a number of 1:1 sessions available for members up to a maximum of 6 one hour sessions. If you are interested, please contact Cherry Mills -cherry.mills@cllsupport.org.uk

We asked, you said, we did

Feedback from the Round Table discussions at the London Conference

We asked delegates at our 20th Anniversary London conference about their experiences and any ideas they had that might be of help to others. We are pleased to share what they said.

What they wished they had known after they were diagnosed

- The importance of developing a list of questions to ask
- The importance of being pleasantly assertive

- The importance of developing an effective relationship with your consultant
- The fact you are entitled to ask for a second opinion
- That they wished they had found out about CLL Support sooner

What they would tell someone who was newly diagnosed

- Be kind to yourself; remember you are the same person before and after diagnosis
- Have someone accompany you to appointments
- Think through who you tell about your diagnosis
- Remember that everyone's situation is different
- Take responsibility for your condition: be your own advocate: run your own case
- At any time, just make the best decision you can
- Educate yourself: make sure you access information from credible sources
- Make a note of any infections you get and keep a spreadsheet with all your results on
- Keep your vaccinations up to date
- Look after your **MEDS: Medicines, Exercise, Diet and Sleep**
- Seek therapy and advice if you feel you need them

How CLL Support has helped people

- The website, information, recordings, conferences and presentations
- The Helpline and the Health Unlocked Group
- Helping you work out what questions to ask consultants
- The feeling that we are all in this together
- Helping you talk to others in the same situation
- Providing support at conferences
- Helping people identify relevant symptoms
- The fact that CLL Support exists

Exercise Study Recruitment

Back in 2021 we held a webinar where we discussed the importance of exercise and nutrition with 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 running a study to assess the benefits of exercise for CLL patients, and they are still recruiting.

Primary Objectives of the study:

- To determine how exercise and diet affect your physical and functional fitness (how well you can get up from your chair etc).
- How these changes relate to your CLL progress, does exercise improve your immune function?

To be eligible, you should:

1. have a confirmed diagnosis of CLL (or Small Lymphocytic Lymphoma)
2. be over the age of 18 years
3. be able to walk on a treadmill or cycle on a static exercise bike
4. be competent in spoken and written English.

What is required from you?

- Commitment of travelling to the University of Surrey a MINIMUM of 1 initial assessment day before the 12-week intervention and 1 assessment day after the intervention – there is the option to do more.
- Commitment of exercising for 3, 1-hour sessions a week, for 12 weeks either:
 - at the University under their supervision OR
 - at home, remotely under semi-supervision (we will provide you with equipment)

NOTE: you may be randomised to a Control group where guidance for physical activity and diet is provided at the beginning ONLY. If you are randomised into the control group, you have the choice to be admitted into any of the exercise groups upon completion of the control phase

Ideally, they are looking for individuals 60+ who exercise less than 3 times per week and are having difficulties getting up from the chair or walking fast, but anyone is welcome!

If you are interested or want more information, please contact Ellie Miles – exerciseoncology@surrey.ac.uk.

This study has been issued a Favourable Ethical Opinion by the University of Surrey Ethics Committee (REF: FHMS 21-22 263 EGA).

Fundraising News



We have so much Fundraising News that we can't fit it all into one newsletter! Click below to read all about what our wonderful fund raisers have been doing over this summer!

[Read our Fundraising News here](#)

Challenge 20 Certificates



A reminder that there is still time to claim your certificate. If you have completed a Challenge during our 20th Anniversary celebrations, please let us know. If you could send us a photo along with a few words telling us about your challenge that would be great. Later in the year we will put all the items together for a special bulletin to celebrate your achievements.

We're looking forward to hearing about what you choose to do – the list is endless and can be as active or as sedentary as you like.

Please email Cherry: cherry.mills@cllsupport.org.uk.

Can you help, please?



Please can you share your CLL story?

For those who attend our conferences, an undoubted highlight is one of our members sharing their CLL story. People find it enormously encouraging to

hear how others coped with their CLL, and to know they aren't alone.

We need people to step forward and tell their CLL stories so that we can feature them at our conferences and in our webinars. If you can't attend in person, we can video you at home.

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: john.greensmyth@cllsupport.org.uk

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



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!