



Newsletter

June 2023 - Issue No 04

Our free helpline: 0800 977 4396

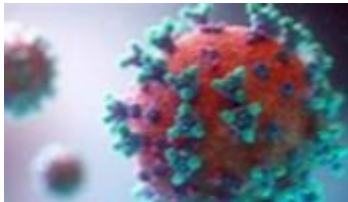
Our top stories in this issue:



Liverpool conference videos now available!



Watch our latest animation!



Important Covid announcement



CLL and physical activity

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



We were so pleased to see fellow members at our Liverpool Conference last month at the very impressive Spine building – and to have others of you join us on Zoom and Facebook.

We are extremely grateful to Professor Andrew Pettitt and his colleagues from Clatterbridge Cancer Centre for giving us their time and their wisdom – and it was so encouraging to hear of their ongoing involvement in the clinical trials which continue to improve the outcome for those of us with CLL. Later in this newsletter are links to the videos of the day so those of you who could not be there can still benefit from their expertise and insight.

One of the sessions was a discussion between CLL patient Moira Griffiths-Parr and Research Nurse Jane Tinsley. Over the years the patient stories at our conferences have been so helpful and this one was no exception. Moira's advice was to treat CLL as an uninvited guest – each time it arrived when she didn't want it, stayed for a while, but then left. She emphasised the importance of positivity – in the CLL world there is always something new round every corner. And finally she reminded us that, like a mobile phone battery, we might not always feel fully charged and we must be kind to ourselves. Very wise words, Moira. Thank you. Again, a key feature of our conferences has been the round table discussions and we are very pleased that a summary of the Liverpool round tables is included below in our 'We asked, You said, We did' section. Being a patient or partner of someone with CLL can feel lonely at times and we hope you will find it helpful to read some thoughts and ideas from others in our CLL community.

Finally a further request for Trustees. I am sure you will appreciate that CLL Support is a patient and supporter-led charity, run by volunteers, who are all keen to give something back to the CLL Community. We are still looking for some more Trustees, in particular people who have website and communication skills. Do please get in touch with me if you feel you might be able to help.

With very best wishes

Hilary Lindsay

Chair, CLL Support

hilary.lindsay@cclsupport.org.uk

Liverpool conference videos now available!



If you missed this conference, where the keynote speaker was Professor Andrew Pettitt, you can catch up with the highlights now.

There was also a wonderful contribution from Dr Stella Williams, and Lead Haematology Research Nurse, Jane Tinsley, had a fascinating discussion with CLL patient Moira Griffiths-Parr. Catch up here:

[Click here for Liverpool Videos](#)

Covid - an important message

Some Covid rules are changing.

You may have received a letter from the NHS already. If not, you should be receiving one soon. The main details of the letter are as follows:

If you get COVID from Tuesday 27 June 2023:

- You will no longer be automatically contacted by the NHS about treatments after reporting a positive COVID test result.
 - You should instead contact your GP practice, NHS 111 or hospital specialist as soon as possible after you test positive so that they can consider referring you for an assessment for treatment.
-

[Click here for the full details](#)

Our new animation launched!

We launched our new animation at our Liverpool Conference. This is a follow-up to our previous animation and is about 'Watch and Wait', or 'Active Monitoring'. It's intended to be a gentle first step to help newly diagnosed patients to come to terms with this difficult time.

You can watch it here. We hope you enjoy!

[Watch the animation here](#)

We asked, you said, we did

Feedback from the Round Table discussion at the Liverpool Conference

Being Diagnosed with CLL is, for both patient and partner, a difficult and transformational time. We asked delegates at the Liverpool conference about their experiences and any ideas they had that might be of help to others. We are pleased to share what they said.

[Liverpool conference responses](#)

Those reading this might also be interested in looking at:

<https://cllsupport-act.org.uk/>

Support ACT is a collection of emotional wellbeing exercises based on Acceptance and Commitment Therapy (ACT) that patients and partners of those with CLL have found very helpful.

Enjoy the sunshine - but...!



A reminder to take care when going out in the sun.

We recommend a good quality SP 50 sunscreen on all exposed surfaces, especially arms and face. Also, always wear a hat.

People with CLL are more likely to develop skin cancer, so:

- Put on protective clothing that covers as much skin as possible.
- Always use sunscreen with a high SPF.
- Put on a hat that has a broad brim.
- Seek shade, and use sunglasses; close-fitting wrap around ones are best.

A patient's story by Alice Scanlon



I was diagnosed with CLL in November 2018. I wasn't ill in anyway but, just visited my GP because I had a small lump on my neck. Initially my GP quite rightly, thought it was connected to some travel vaccinations but when it didn't go down (it never changed at all), I was sent for an ultrasound.

The excellent radiographer was concerned that I may have had Myeloma and sent me off to see a Maxiofacial consultant with a view to a biopsy. This showed nothing to take a biopsy from so I was referred for a full blood count. Three weeks on from that second GP's visit I was sent an appointment to see a consultant haematologist.

Then the bombshell!!! I was told that I had Chronic Lymphocytic Leukaemia, I only heard Leukaemia and I thought I was going to die. I couldn't understand why I wasn't being treated apart from blood tests. Once it was all explained, I felt better and tried to live normally.

Then came the Covid19 Pandemic and our travel wings were clipped. In August 2021 I was told that it might be better to start treatment so I started with Acalabrutinib. What a wonder drug!. I tolerate this very well and thankfully my blood has responded well. My blood counts are now in normal numbers and I am told that I have good partial remission.

Seven Covid19 jabs but still no antibodies, so we wear masks and try to avoid crowds. We have, with the help of FFP3 masks, begun to travel again in Europe.

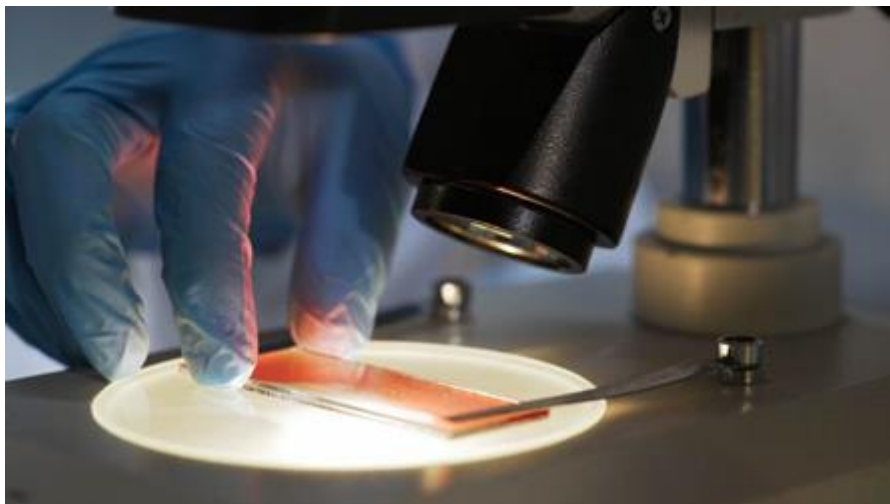
I publicise my experience as much as I possibly can in hope that others will seek medical help perhaps earlier. I think I possibly had CLL much longer but undiagnosed. I had suffered drenching night sweats and extreme tiredness but always had other reasons, - menopause, I had been extra busy etc etc.

I now help Leukaemia Care by being a member of the buddy team and will happily help anyone who is in need.

I was in the early stages of setting up a support group in East Yorkshire but like so many other activities, covid put the brakes on. I would like to get this a bit more operational but we have all to be careful. My husband (Tony) and I are active members of U3A where we were leading groups for gardening, wine appreciation, photography and family history. Slowly we are getting back to some of these but meeting outside.

Our thanks to Alice for sharing her story. If you have a story you would like to share, please do contact us at: briangardom@cllsupport.org.uk

Hearing about CLL patient's stories really helps others to know they are not alone.



**September 2023 is Blood Cancer Awareness Month and
September 1st is CLL Awareness Day.**

We need your help, please!

Last year's campaign highlighted how you "Live Well with CLL". We know that not everyone feels they can 'Live well with CLL', and this year's theme will be:

"Impacts and Consequences".

We would like to create three separate videos with the following titles:

- **Impact of Diagnosis**
- **Impact of Treatment**
- **Consequences of Living with CLL**

So what do we need from you? Quite simply, we need to hear about your experiences under the above headings. We would like either a very short video, or a photo with accompanying text explaining how you have been impacted by your diagnosis, the treatment you've received (or not if you are on Active Monitoring / Watch & Wait) and the consequences of living with CLL. We especially want to hear from family members, as our recent survey shows that family members have been affected quite significantly by a partner's / relative's diagnosis.

Please send your contributions to Sarah at membership@cclsupport.org.uk. If you have any questions please contact John Greensmyth at:

john.greensmyth@cclsupport.org.uk

Please send your responses by Friday 30th June. Thank you!

Health matters

Can physical activity help people with CLL?



Physical activity can help support quality of life and improve physical fitness in adults with CLL, according to new results of a pilot study, the conclusion was:

"Specifically, the data showed a physical activity intervention increased leisure time physical activity in patients and decreased fatigue. These changes were associated with an increased CD4:CD8 T-cell ratio and reduced proportion of T-cell subsets that have previously been associated with poor outcomes in patients with CLL."

You can find the full report here:

[Physical Activity Improves Quality of Life, Fitness Among Older Adults With CLL \(ajmc.com\)](https://ajmc.com)

For those who are able to exercise, this is very encouraging information. However, always check with your medical team if you are considering starting an exercise programme. Always begin gently and gradually build up.

Do you, or someone you know, suffer from long Covid?

Long Covid Support (<https://www.longcovid.org/>) is a patient-led charity providing support and information to those affected by Long Covid. They run a large, international support group on Facebook. The group is carefully moderated to provide a safe space for discussion, moral support and the sharing of information.

<https://www.facebook.com/groups/longcovid>

They run specific events which are advertised in the events section of the group, such as pacing sessions, opera breathing, check-in and chat, chair yoga etc. Anyone who has long Covid themselves, or is personally caring for a loved one with Long Covid, is welcome to join the support group.

They also run a research group which focuses on discussing the results of scientific research, promotes patient involvement in research and provides a place for researchers to promote and advertise their research studies. This group is open to anyone who wishes to join.

<https://www.facebook.com/groups/2590602557864509>

Other News



Following the huge success of our earlier emotional wellbeing programme, Support ACT Round 2 Group Drop-ins will be starting later this Summer - six sessions on either Thursday mornings or Tuesday evenings. More details will be announced soon when dates have been confirmed so keep an eye on your emails!

More fundraising

The contribution to our fundraising from our members is amazing. Here are just a few examples of their efforts. We are extremely grateful to everyone, and without you, we would not be able to carry on our work. You are all stars! Thank you!



David Lawton took part in the Kings Lynn 10 on Sunday 30th April. He completed the event in 1 hour 10 minutes. He tells me that he hasn't run this far in 30 years. At the time of writing, Dave had raised £645 for CLL Support, a charity close to his heart.

If David has inspired you to take part in a fundraising event yourself, please contact me for a fundraising pack:

cherry.mills@cllsupport.org.uk



A big thank you and well done to Pam Morris who held a coffee morning recently to raise funds for CLL Support. Pam has CLL and wanted to hold a fundraiser herself. Her daughter Lianne is planning to do some fundraising in the Summer. More details of this to follow.

Pam invited some of her friends and between them they raised an amazing £265.

A couple of these friends, Pauline Stowe and Audrey Pearson, are members too - they met at one of our conferences. They discovered they lived close enough to keep in

touch and meet up for coffee and have remained friends ever since. It's so lovely to hear about our members making friends through our conferences.

Another amazing effort!



Chris Else ran 10K (6 miles) every day throughout the month of May! His objective was to raise money for CLL Support and to raise awareness of the condition. He's absolutely smashed his fundraising goal of £200 and at the time of writing this article, he had reached the amazing total of £919!!



Chris's stepdad was recently diagnosed with CLL so Chris felt that the least he could do was to raise some money for CLL Support whilst challenging himself both physically and mentally.

When Chris started the challenge, he invited people to join him on his runs if they wanted to.

On behalf of all of us at CLL Support, both Trustees and members, a massive thank you to Chris for his fantastic fundraising. You really will make a difference!

Check out Chris's fundraising page, the link is below:

<https://www.justgiving.com/page/christopher-else-1679042496640>

For anyone out there who feels inspired by Chris to take on a challenge,

be it physical, mental, or something completely different, please email me: cherry.mills@cillsupport.org.uk. I would love to hear from you and I can send you out a Fundraising Pack to help you get started.



For all those runners among you, the ASICS London 10K takes place on Sunday 9th July this year.

It is the most iconic capital city 10K race with live bands, DJs and cheering fans to motivate you all along the River Thames, Westminster Bridge and by Big Ben. Sounds amazing and what a great sense of personal achievement when you reach the finish line.

Tickets are being advertised now at £45 (plus £3.15 entry fee) each and are available by clicking on the link: [ASICS London 10K | Limelight Sports Club](#)

Refund for Event Fees

Are you thinking about taking part in an organised fundraising event? We may be able to refund all or part of your entrance fee up to a maximum of £50 depending on demand. All you need to do is agree to fundraise a minimum

amount for CLL Support. For more information or for a pledge form and fundraising pack, please email: cherry.mills@cllsupport.org.uk



We have recently registered with the Fundraising Regulator so you will see the above logo appearing on our website and fundraising materials. By registering CLL Support with the Fundraising Regulator, it shows that we are committed to fundraising in a way that is legal, open, honest and respectful in line with the Code of Fundraising Practices.

Now that Smile.Amazon has come to an end, a part of our income has been lost. You may be looking for an alternative to sign up to.

Below are a couple of options. Sign up for free and raise money when you shop online. It could be your weekly food shop, a holiday, annual insurance, household appliance, etc. **At no additional cost to you**, it's really easy to raise money for us. It just takes a few minutes of your time to sign up.



easyfundraising - <https://www.easyfundraising.org.uk/>

easyfundraising partners with over 7,000 brands who pay it a commission when people start their shop via its site or app. It then turns this into a donation for your chosen cause. You can see how much you've raised for CLL Support, and get updates on when we get paid.



Charitable shopping - <https://www.charitable.shopping/>

When you buy through Charitable Shopping, its partner shops and service providers pay it a 'thank you' fee, which it transfers over to the charity. The donations are sent through JustGiving to the charity directly. Supporters can register, select their charity, and start donating straight away.

Why not give it a try - it's easy

If you have fundraised for us do please let us know so that we can thank you and perhaps feature you here.

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: lewis.troke@cllsupport.org.uk.

Many thanks

Marc Auckland

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](#)

**Do you have a will? If not, we can help
Or perhaps you need to change your will? We can help, too.
And it's free!!**



Our new free Will-writing service.

We do understand that the decision to write a will can be a delicate topic and must be handled sensitively. But it is essential for most people to have a will in order to safeguard their interests after death.

It would be wonderful if you could read on before deciding if this is something you wish to do.

CLL Support is a member of **The National Free Wills Network which gives us the opportunity to offer a limited number of valid 'simple' Wills (or mirror Wills for a couple) **entirely free of charge and written by a solicitor local to you.****

There is no obligation whatsoever to include a gift to CLL Support in your Will, but we sincerely hope that you might consider doing so.

How does it work?

1. You tell us you are interested in using this service.
2. We refer your details to The Free Will Network. Your details are not shared with anyone else and the Network will only contact you to provide the service, never for marketing.
3. The Network send you a list of your nearest participating solicitors and a voucher to take to your appointment.
4. You meet with the solicitor at an office local to you (or online if you prefer) to discuss your wishes and prepare your Will in the usual way. Most Wills are completely covered by the free Will service. If your Will is more complex, your solicitor will advise you of this, giving you the option to continue and pay the difference if you wish.
5. Once you have made your Will, the Network tells us if your Will includes a gift to CLL Support so that we can write to thank you.

It's a very discrete and straightforward process, and if you would like more information, please ask for a copy of our explanatory leaflet here:

coordinator@cllsupport.org.uk

Or download from our website [here](#):



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!

