



Newsletter

April 2024

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



We trust you are all enjoying the extra hours of daylight we are all experiencing.

During the darker days of winter your charity was not idle. In January and February, we hosted three evening webinars which the UK CLL Forum ran for haematologists, specialists and other health care providers involved with CLL. One of the sessions CLL Support's Vice Chair, John Greensmyth and Associate Leilia Duley who are able to present to the specialists the views of the CLL community about how the news of their diagnosis was shared with them. Thank you to the 500+ of you who completed the survey which informed the presentation. If you would like to view their or any other of the presentations you can do so [here](#)

You will read elsewhere in this newsletter about our recent Conference in Poole and our Flair and Static Webinar. Do make a note of the date of our next conference which will be held in York on Tuesday 18th June. You may well have noticed that this week we launched our 20th Anniversary Celebrations – a very exciting time for us all and an opportunity to reflect on how the CLL treatment has been transformed over that period. It would be fantastic if you could all get involved in some way with what we are doing.

My final request is to ask those of you who have not yet done so to spend ten minutes completing our two-yearly survey. The details are immediately below this piece. We are here to represent the CLL community, and your responses will enable us to speak on your behalf on the issues that concern you.

With my very best wishes.

Hilary Lindsay

Chair, CLL Support

hilary.lindsay@cllsupport.org.uk

[Complete the CLL Support Members' Survey Here](#)

HEALTH MATTERS

An Update on the Flair and Static Trials

On 30th January we were delighted to welcome Dr Talha Munir, Professor Adrian Bloor, Dr David Allsup, Lelia Duley and Rhiannon Lambkin to speak on our webinar on evolving clinical trials. We heard not only about the FLAIR and STATIC trials but also more widely about the benefits clinical trials can bring. 150 of you were on the call. Of those completing the exit polls, most of you had little or no knowledge of the STATIC and FLAIR trials before the call, 89% of you said you were now more likely to consider a trial option if offered and appropriate to your needs and 100% of you felt trials were a valuable option to be considered by CLL patients. You can view a recording of the webinar [here](#) and access the latest update on the STATIC trial [here](#).

More generally, the Trustees at CLL Support are very keen to do what we can to both support trials and encourage the effective PPIE (Patient and Public

Involvement and Engagement). We will be sharing more of our ideas before too long.

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The CLL Society have published a useful piece of trial research on Ibrutinib from the FLAIR trial for those who complete the trial and come off the drug and what their disease progression is likely to be

<https://cllsociety.org/2023/11/is-it-safe-to-stop-ibrutinib-therapy-for-cll-after-multiple-years/>

NHS Patient choices

Have you seen this information from NHS website which says 'Did you know that in many cases you have the legal right to choose where you have your NHS treatment?' You can read more about it on their

website: <https://www.nhs.uk/using-the-nhs/about-the-nhs/your-choices-in-the-nhs/>

We haven't had personal experience of this and would be interested to hear from our members who have followed the advice on the NHS site and how it worked in practice. Email us at membership@cllsupport.org.uk

A message from the UK CLL Forum about their IVIG Survey

Thank you to everyone who completed this survey so far. We urgently need more numbers to make it really meaningful. Please can you complete this short survey if you have ever had Immunoglobulin therapy or are currently receiving Immunoglobulin therapy. No personal identifiable information will be requested. Please do NOT complete this survey if you think you did so towards the end of 2023.

CLL has been associated with low immunity, poor vaccine responses and

increased risk of infection. Immunoglobulin replacement therapy (IVIG) is sometimes used in those most affected.

There is little data behind how Immunoglobulin therapy is being used in the UK. It is very important that we understand more about patient experience with Immunoglobulin treatment.

By completing this survey, you will help people with CLL

Thank you from the UK CLL Forum

[Complete the IVIG Survey here](#)

MEMBERS' NEWS

POOLE CONFERENCE
14TH MARCH 2024



Our Conference on 14th March at the RNLi College in Poole was another resounding success. We went to the south coast in part to fulfil an outstanding wish of former Trustee Lewis Troke who sadly died last year but had lived near Winchester. We were delighted that Lewis's wife Heather, already a close friend of CLL support, was able to join us. The theme of the Conference was 'Navigating Treatment Pathways Beyond Chemotherapy'.

In her opening remarks CLL Support Chair Hilary Lindsay commented: 'CLL is heterogeneous; it affects everyone differently. Over recent years

treatments for CLL have developed at an amazing pace. Therapies are becoming ever more focused with fewer side effects. How a therapy is given to a patient is becoming increasingly tailored to that patient's needs. These are exciting and promising times.'

Hilary then invited Professor Francesco Forconi to give the Lewis Troke Memorial Lecture on a subject that she knew was dear to his heart: 'How clinical science can push boundaries for specific patient needs: the development of targeted therapies in CLL'. Other speakers and panellists on the day included the Chair of the UK CLL Forum, Dr Renata Walewska, Clinical Nurse Specialist Bryony Tyrrell, Dr Helen McCarthy and Dr David Dutton.

CLL Trustee Norah Grant shared her patient story in a way that was inspiring and entertaining, David Warner shared his plans to walk from John O'Groats to Lands End and hopefully enter the Guinness Book of Records and John Greensmyth shared his plans and showed off the recumbent bike he will be using to cycle in the opposite direction. Both endeavours are to raise fund for CLL Support's 20th Anniversary Challenge.

The Conference ended with round table discussions in the room and (for the first time) break out rooms on Zoom where those attending had a chance to share their experiences with others in similar situations.

As ever the formula of hearing from leading edge experts and to meet with others with CLL and their partners proved a compelling offering. Recordings of the presentations can be accessed [here](#) soon.

MyCLLife

AbbVie have announced that they have closed their MyCLLife text service. They have notified subscribers and have added the following statement:

'Supporting people with CLL is still incredibly important to us. As such, we will be creating an online MyCLLife Hub to house all our existing MyCLLife resources, ensuring that people living with CLL continue to have access to useful information, tools and resources that have been developed in partnership with the community'

We look forward to seeing their new online hub soon



"It's with the deepest regret that we announce the passing on 14 January of our friend and member, Alice Scanlon, having contracted a severe form of Covid whilst on holiday.

Alice spoke movingly at our conferences about her CLL Journey, wrote about her experience as a CLL patient for our newsletter, and was an advocate for the CLL cause, having been interviewed by her local newspaper to raise the profile of CLL. She was a caring and giving person who helped others by joining our buddy scheme with Leukaemia Care.

Our deepest condolences are sent to her devoted husband Tony and her family and friends. "

We asked, You said, We did

We knew you were all always interested in hearing patient stories at our conferences and also in the round table discussions we had. We had also found some of you who came to the SupportACT monthly sessions welcomed the opportunity to have a chat at the end. So last month we took the two ideas online with our first Check in and Chat webinar on the afternoon of December 11th.

First we heard again from David Warner who had spoken about his patient story at our Birmingham conference in December 2022. In his pre-recorded interview with Vice Chair John Greensmyth he not only shared his intrepid travel stories over the last year but also that he was planning this Spring to walk from John O'Groats to Lands End to raise funds for CLL Support!! We were all so pleased and excited to hear this! Indeed some of you were offering on the spot to accompany David on various stages. Rest assured that we will be letting you have more news about David's venture as we get nearer to it.

We then went into break out rooms where we were able to share our own experiences and talk about David's amazing example of taking exercise! We agreed it was important to have some motivation to encourage us all to do some exercise on a regular basis – whether that be discipline or reward-based! We also recognised the importance of keeping all our vaccinations up-to-date, particularly over the winter months. To help you can download our Vaccination passport from here - <https://cllsupport.org.uk/information-support/further-information-resources/order-publications/> You may also be interested in our newly-updated treatment page – <https://cllsupport.org.uk/information-support/about-cll/cil-treatment/>.

Our first Check in and Chat was an undoubted success and we will be running more. Do please get in touch with John Greensmyth (john.greensmyth@cllsupport.org.uk) if you have previously spoken about your patient story at one of our conferences and are willing to share an update with us all.

HEALTH UNLOCKED

Founded and developed by a CLL Support Trustee, Health Unlocked is our online forum.

Here you will find reliable advice and information from other CLL and SLL

patients and supporters and a warm welcome. We now have over 22,000 members from all over the world, and it is closely monitored by our administrators and volunteers, and we are indebted to them for their knowledge, dedication, and hard work.

If you would like to become a member of Health Unlocked and meet other people with CLL you can sign up [here](#). Just click on the box at the top right of the screen that says join.

Some of the comments from members:

“...I don’t exaggerate when I say this forum saved my life.”

“Thank you so much for the help and advice. I don’t know what I would have done without it.”

“Being part of this community has helped me enormously...”

Check it out, it’s simple to join and we are sure you will find it helpful. Please read the [HealthUnlocked Guidelines](#) before using the online form. We look forward to welcoming you!

FUNDRAISING UPDATE



This year marks the 20th Anniversary of CLL Support. We launched our anniversary Campaign on the 25th March with a webinar for our members - please keep an eye out for our newsletter and bulletins throughout the year.

During our webinar we launched our 'Challenge 20'.scheme. you can find more information by reading

our fundraising newsletter here. Our intention is for this to include a range of physical and mental well-being activities that everyone can take part in You may have your own idea's for this so please feel free to share with us. The list is potentially endless – it doesn't have to be physical, it could be related to your hobbies or it could be linked to our Support ACT and incorporate well-being exercises. Anyone taking part and completing their challenge will receive a Certificate. Details on how to register will be published nearer the launch date.

We are looking forward to hearing from you about your own fundraising events or how you are celebrating our 20th Anniversary and will look forward to publishing your stories in our Newsletter's.

**Join us for a walk around Grafham Water
Sunday 23rd June 2024**



The walk will start at 10:30 at the Grafham Water Car Park near Marlow Park, Buckden Road. The meeting point will be the pay-station next to the visitor centre. Please allow time for parking, refreshments, etc.

From the meeting point we will walk to the café, Harbour View at the Fishing lodge, for 12:30 Please bring a picnic and maybe a mat for sitting on the grass. The cafe may be very crowded. This will be an opportunity to chat to some of the trustees and members of CLL Support, perhaps meeting with people you've chatted to in the U60's group.

After lunch the walk can continue either clockwise for the long walk or anti-clockwise back to Marlow Park via the shorter route. The full, longer, walk is 20,000 steps. We will be issuing certificates to those of you taking part who would like one.

It would be fantastic if you could get family and friends to sponsor you. A link to our Just Giving page is below. You can make a single donation or set up your own page from there should you wish to do so.

<https://www.justgiving.com/campaign/clltwenty>

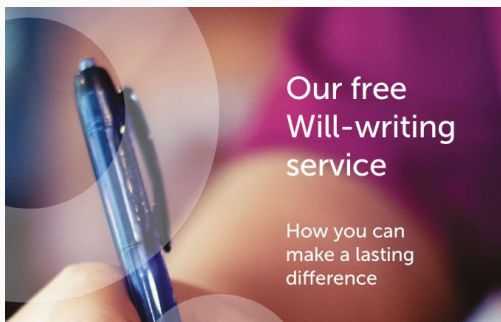
If you prefer not to actively fundraise but would like to join us on the walk that is absolutely fine and it will be lovely to see you.

Please get in touch to register with us if you are interested in taking part:
cherry.mills@cllsupport.org.uk

We already have a WhatsApp group set up for interested walkers ready to add you too if you decide to join us. We will be sending out reminders before the big day. Keep an eye on your emails.

If it's too far to travel, you might like to have your own 'virtual' walk on the 23rd June. If you do, please send us photographs so we can include you all in our follow-up news on our website, newsletter and social media.

[With so many people to thank and so much happening for our 20th Anniversary and Fundraising we have published an extra Fundraising Newsletter. To find out more click here....](#)



Did you know that CLL Support offer a free wills writing service. You can download our leaflet for further details or if you would like to be referred to the Free Wills Network send your name and address to cherry.mills@cllsupport and she can arrange for them to send you an information pack with information about the next steps.

<https://images.cllsupport.org.uk/wp->

[content/uploads/2020/09/08101932/CLL-Legacy-leaflet.pdf](https://images.cllsupport.org.uk/wp-content/uploads/2020/09/08101932/CLL-Legacy-leaflet.pdf)



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!