



Newsletter

September 2023 - Issue No 05

Our free helpline: 0800 977

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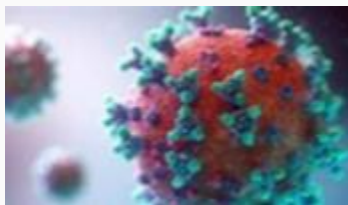
Our top stories in this issue:



London conference bookings open



Watch our BCAM videos



Our Latest Vaccination update



Cycology

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



You may well have read already about the sad death last month of Trustee Lewis Troke. Lewis was a tireless supporter and advocate of the CLL community. His legacy very much lies in the impressive conferences and webinars he organised for us – you can see their full extent at <https://cllsupport.org.uk/news-events/conference-reports/>.

We have now taken up Lewis's baton and, led by Vice Chair John Greensmyth, were so pleased to hold our Welsh Conference on 4th September at Sophia Gardens in Cardiff, Glamorgan Cricket Club's home. During the day we were able to bring a holistic approach to how we live with CLL as we heard from Consultant Haematologist Dr Nilima Parry-Jones, Clinical Psychologist Anne Johnson, Clinical Nurse Specialists Tracey Guner and Sian Poore and patients Kate Giles, Diane George and Dan Cherry from Aneurin Bevan Hospital and from Dr Frankie Brown from Bath University who talked about the benefit of exercise. It was an inspiring day for those of us who could be there or attend on Zoom and the recordings will soon be available on our website so others of you can benefit.

There can't be many events where one of the three main speakers had run 13 miles the day before, another had scaled Ben Nevis and the third arrived on her Brompton bike, making several of my Trustee colleagues very jealous!! I think everyone was very much practising what they were preaching.

Again a key feature of our conferences was the round table discussion and we are very pleased that a summary of the Cardiff 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. In his concluding remarks, John Greensmyth commented that if you take the 'i' from the start of 'illness' and replace it with 'we', you get 'wellness'. While sharing with others won't cure you, it's likely to make you feel better which is what we mean by 'wellness'. Certainly the day made me realise the importance of being part of a community and that is what we are aiming for at CLL Support, whether that be through our website and newsletters, or our conferences and webinars. There is of course no 'i' in 'team' and we are all in this together.

If you are wishing you could have been at Cardiff, you now have an opportunity to book for our London Conference on Thursday October 26th. Details are on our website and also in this newsletter. We look forward to seeing many of you there.

With very best wishes
Hilary Lindsay
Chair, CLL Support
hilary.lindsay@cllsupport.org.uk

London Conference bookings are now open!

LONDON CONFERENCE

26TH OCTOBER 2023



**You are invited to our London Conference on Thursday
26th October 2023**

10:00am to 4:00pm at 11 Cavendish Square, London, W1G 0AN. We are privileged to have as our keynote speakers Dr Samir Agrawal and Pinky Jimenez-Agrawal.

[Book a place here](#)

Medical Matters

Covid Vaccinations

From the 11th September Vaccinations are now available for immunocompromised patients and their close family members and can be booked using local booking services. You can also book via the national booking service from the 18th September.

[More details here](#)

One of the most frequent questions we are asked is: "Should I have the flu and Covid vaccinations at the same time?"

The concern is that if both vaccines are given at the same appointment, the body's immune response to one or both might be blunted, leading to lower effectiveness.

Last year, the Centre for Disease Control (CDC) in America said it was fine to get both at once. This was based on research that looked at immune responses when one of the doses in the primary Covid vaccine series and an annual flu shot were given together.

The conclusion? Safety: (It's fine) Effectiveness: (It's good). There is also the consideration that you could catch the infection you haven't been vaccinated for, before receiving the next one. It should be noted that this research was not done in people with blood cancer, but, theoretically, there should be no difference.

You can find further details [here](#)

Scottish Medicines Consortium (SMC) Approves use of Ibrutinib and Venetoclax in combination

On Monday 11th September the SMC announced the approval of Ibrutinib and Venetoclax in combination as a first line treatment option for previously untreated patients. The drugs will be available via a PAS (Patient Access Scheme).

Background;

The SMC is the body in Scotland which considers and approves medicines for use within NHS Scotland. CLL Support compiled a Patient Group Submission document in early June and then participated in a PACE Meeting (Patient and Clinician Engagement) in early July. The final step in the process was the full SMC committee meeting on 1st August and again CLL Support attended and presented the patient's perspective.

This is good news for CLL Patients in Scotland and follows similar approval for I&V by NICE in England earlier this year. It also demonstrates CLL Support's advocacy on behalf of our members in Scotland.

We asked, you said, we did

Feedback from the Round Table discussion at the Cardiff Conference

The theme of the conference was 'Keeping well during all stages of CLL'. During the day we heard about keeping well while on active monitoring, coping with uncertainty, the impact of exercise and current treatment pathways, as well as hearing about the experiences of patients and clinical nurse specialists. Below are the three questions the groups were asked to consider and their responses...

[To read the full feedback click here..](#)

Those reading about the round table discussion 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.

Support ACT Round 2



We're very pleased that we can now offer further support by launching Round 2 of our very popular free online drop-in sessions.

Round two has already started on Thursday 7th September at 10:00. The next session will be on Tuesday 19th September 19:00. Please

email cherry.mills@cilsupport.org.uk if you would like to join in.

september is

Blood Cancer
AWARENESS
MONTH



September 2023 is Blood Cancer Awareness Month
This year's theme is
"Impacts and Consequences"

We have created three separate videos with the following titles:

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

We have already launched all of the videos which you can find on the news page of our website: <https://cllsupport.org.uk/news-events/news/>

We would like to send our thanks to all of the members that offered their stories, photos and videos to help make this happen. Also we would like to thank one of our members, Alison Fraser who produced the videos alongside her brilliant team.

Health matters



CYCOLOGY

The title is clearly a play on words so let's hear from one of our Trustees; John Greensmyth, on what's behind this.

"I've always had a bike of some description but I've never been part of a cycling club or (perish the thought) raced competitively. As a family we had

the usual collection of bikes and enjoyed getting out and about. When I was working and trying to keep fit I started going out with friends for a spin at lunchtime but I was always “tail end Charlie” or the “Lantern Rouge” as they say at the Tour de France. I found cycling easier than running and better for my knees as the years flew past. So I then bought a ‘proper road bike’ and even invested in Lycra!! However after a severe bout of Haemolytic Anemia, the bike gathered dust in the garage. Along came Ibrutinib and my health improved dramatically. At clinic I asked what I could do to be in the best shape I could be to fight my CLL, Jeff the CNS, suggested I try a Macmillan Move More course in 2014. This was life changing as it gave me the confidence to start exercising again and I eventually dusted off my bike.

As I live in rural Aberdeenshire we are fortunate to have plenty of quiet, scenic roads to cycle on. I started to increase my range and my average speed also increased. Not only did my fitness improve but I noticed a positive mood swing - mind you, I can still give Victor Meldrew a run for his money - but I definitely felt better mentally. Getting out in the countryside with beautiful scenery in every season is uplifting and doing so with a raised heart rate brings added physical benefits. I now have several bikes and I’ve gone full MAMIL (Middle aged Man In Lycra) or OMIL in my case (Old!). I’ve built up my fitness to such a level that I have now done several closed road cycling events - the highlight of which was Ride London last year whilst raising funds for CLL Support. I enjoy my time in the saddle and the feel good factor of blending ‘my time’ with physical exercise has delivered unexpected benefits to me (and those who live with me !!). I’m also a rugby fan and in 2019 I set myself a “6 Nations Challenge” - to cycle in an event or on a noted route in each of the nations that comprise the 6 Nations competition. The highlight of that challenge was reaching the summit of the Galibier in France - it’s a tough climb but an epic route and often features in the Tour de France. I was probably the slowest ever recorded time but the only person I compete with is me and that’s just to improve and make sure I still enjoy my saddle time. The sense of achievement on reaching the summit was enormous and really uplifting. Time spent on the saddle is a happy time for me and I usually have a big smile on my face - unless I’m tackling a steep climb....

Clearly I’d recommend cycling to anyone able to get on a bike, start slowly and carefully and bit by bit increase your distance and then try a gentle hill or two. I enjoy cycling on my own, where my thoughts can wander, or cycling with the company of a couple of friends and at a pace where we can chat. I’m not a fan of a big cycling group and I always pull in for other vehicles - I drive many more miles than I ride so I see both sides of the ‘debate’. But the benefits I’ve gained from the physical effort and mental calmness mean my brand of “**CYCOLOGY**” works for me. Oh, did I mention the main benefit?

Because of the number of calories burned on a bike ride, a coffee and cake stop is a guilt free indulgence to be enjoyed on every spin !!!

Take part in a Study to empower Blood Cancer Patients

Let us introduce Kirsty Crozier, a professional doctorate Student at Oxford Brookes University who is conducting the following study:

'The idea behind the study is to help support blood cancer patients in the longer term by empowering them to self manage their symptoms and condition, given these are chronic issues. I am seeking the response of approx 250 blood cancer patients, and then hope to interview 10-20 for more a more in depth understanding of what self management they have tried, why and what the barriers may be'

It is an online study and if you would like to take part in the survey you can access it here:

https://brookeshls.co1.qualtrics.com/jfe/form/SV_ah0mG3nf5BfidTM

If you have a query or would like any further information about the survey please contact Kirsty: kirsty.crozier@nhs.net



Cancer52 represents over 100 predominantly small patient support group cancer charities united by their vision of seeing a better future for everyone affected by the rare and less common cancers, which account for more than half of all cancer deaths in the UK.

They are carrying out a survey on travel insurance for cancer patients. Here is a link to the survey if you would like to take part: <https://www.surveymonkey.co.uk/r/S952DN7>

[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!



On the 3rd of October 2023, a group of firefighters from Feltham Green Watch will be undertaking the National 24hr Three Peaks Challenge with the aim of raising money for CLL Support and two other charities.

Their challenge involves walking the highest peaks in England, Scotland and Wales, all in 24 hours.

The Start is Ben Nevis in Scotland (1345M), followed by Scafell Pike in England (978M), finishing on Yr Wyddfa (Snowdon) in Wales (1085M). The total driving distance is 462 miles, the total walking distance is 23 miles and the total ascent is 3064 meters.

CLL Support have been supporting Green Watch colleague Tristan who was diagnosed with Chronic Lymphocytic Leukaemia last year. Tristan has found the online materials and information provided on the CLL Support website invaluable to him. The information provided on the website was one of the first places he read up on the condition and is grateful for the important work we are doing. Tristan is on the start of his journey living with Chronic Lymphocytic Leukaemia and has chosen CLL Support as a charity that he wants the funds raised to go to, so CLL Support can continue to help and support others in the same way in the future.

If you are interested in sponsoring Green Watch, please follow the link to their peoples fundraising page.

<https://www.peoplesfundraising.com/fundraising/feltham-green->

[watch-three-peaks-challenge-](#)

On behalf of Jamie, Mike F, Kelly, Nick, Craig F, Jim B, Mike H, Craig M, Tristan, Jim T and Toby, thank you.

I'm sure you will all join us at CLL Support in wishing Green Watch the very best with their challenge.



You may remember from an earlier Newsletter that Sarah Jones was taking to the skies this month to complete a tandem Skydive. We're pleased to report that Sarah completed her Skydive on Saturday and really enjoyed the experience.

From the photo's it looks like it was a beautiful day. Please join us in a huge 'Well done' on doing the Skydive and for fundraising for us too.

Sarah has chosen to raise money for the CLL Support Association and had originally set her target as £325. At the time of writing she had smashed this target raising £920. On behalf of all of us at CLL Support, thank you so much Sarah for your amazing fundraising and for raising awareness of CLL.

We've included the link to her fundraising page below should anyone wish to make a donation.

<https://www.justgiving.com/fundraising/sarahnjones>

Maybe Sarah has inspired some of you to take to the skies or to take part in your own personal challenge. If so, please get in

touch: cherry.mills@cllsupport.org.uk

Another amazing effort!



Andrew Stow decided to do a sponsored walk in the Malvern Hills to celebrate his 77th birthday.

He unfortunately contracted Covid but this didn't put him off and he completed the walk on his 77 ½ birthday instead! On the 8th July Andrew set off at Chase End Hill. His route consisted of another 6 ascents climbing a total of 607 meters and descending 405 meters until he reached North Hill.



Andrew was ably assisted by his grandson Benji who designed his own sponsorship form and raised £162 by himself in sponsorship. Together they raised a total of £440

Local friends also joined along the way to support Andrew and Benji and everyone at CLL Support is very grateful for their brilliant fund raising.

From their photo it looks like an amazing view and what a great team Benji and his Grandad made!

You may remember from our last Newsletter that Lianne Redden's mum Pam Morris recently held a coffee morning to raise funds for CLL Support and to get Lianne started with her own fundraising this year.

Since then Lianne took part in a very hilly Trail Half Marathon on 16th July along with her son Jude and her brother Gavin. Lianne is a very proud mum as it was Jude's first running event. They did the event in good time – 2 hours 14 minutes.

Lianne also took part in a road half marathon on 13th August in Solihull and is hoping to be joined by both her son's.

The link to Lianne's Just Giving page is below. At the time of writing, she had raised an amazing £569. Brilliant Lianne, well done and a huge thank you from all of us at CLL Support.

<https://www.justgiving.com/page/lianne-redden-1682438063100>

Mikey Gibbs successfully completed the 3k recently raising £240. The weather forecast wasn't great but in the end it was kind to Mikey and the other runners with just the wind to contend with! Well done Mikey from all of us at CLL Support Association.

