

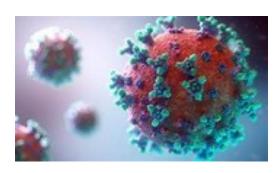
Our top stories in this newsletter











Latest webinar with Prof. Hillmen

Corona virus Update



A message from Marc Auckland, CLL Support Chair.

The news surrounding the Covid-19 vaccination programme has certainly lifted spirits, but, understandably, it has also generated a lot of questions from members. We have addressed many of these on our website, and you can find details later in this newsletter. Even though we may be edging towards the end of the lockdown, Covid-19 is still a highly active area, particularly in research, with new information coming out daily and we will do our best to keep you up to date.

As a voice for CLL and SLL patients, we continue to put forward to policy makers ideas that matter to our members . As you will see below, we have joined with other charities to lobby the government on key issues, and we will continue to do so. Our experience tells us that by joining together we have a louder voice and can make real changes.

We had some excellent news earlier this month with the approval by NICE of a new treatment, acalabrutinib, and I was very pleased to be asked by Sky News to comment on this development in their early morning news programme. In addition, there was coverage in all national newspapers. We do believe that this is a step-change in the treatment of CLL, and you can find full details on our website.

Finally, I would like to offer a heart-felt thanks to the generosity of our members who have so kindly donated or taken up our free will writing offer. At this time of so many unknowns, it gives me great strength to know that with you on our side we will be able to carry on our work of supporting you, our members.

Wishing you and your loved ones good health.

Marc Auckland Chair of trustees marc.auckland@cllsupport.org.uk



Excellent news on a new treatment!

We are delighted to announce that NICE has recommended acalabrutinib for people with:

- untreated chronic lymphocytic leukaemia and a 17p deletion/TP53 mutation or
- untreated chronic lymphocytic leukaemia without 17p deletion/TP53 mutation, and • fludarabine plus cyclophosphamide and rituximab, or bendamustine plus retuximab, is unsuitable

or

previously treated chronic lymphocytic leukaemia •

Our patient advocate, Jackie Martin, made the submission to NICE on behalf of ourselves and Lymphoma Action. Together with Leukaemia Care and the clinical experts she gave evidence at the Committee Meeting outlining the benefits for patients of acalabrutinib. We are delighted that approval has been published after all the hard work.

We are incredibly pleased with this announcement, which we believe will have a profound effect on patient care.

Our Chair, Marc Auckland was interviewed on Sky news on 18 March about this exciting new treatment.



LEUKAEMIA PATIENTS TO BENEFIT FROM NEW TREATMENT AS HEALTH OFFICIALS APPROVE IT FOR USE ON THE NHS LEUKAEMIA TREATMENT

We also provided quotes for the national press. After so much effort, it's very pleasing that NICE has granted approval.

There are other treatments and combination treatments currently in the pipeline, and this is an exciting time for CLL patients. We'll be sure to keep you informed.



Our recent webinar now available on video **Professor Peter Hillmen** 18 March 2021

We were very pleased to welcome Prof. Hillmen as our keynote speaker. His talk was:

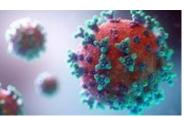
'Where next for treatment in CLL/SLL?'

Prof. Peter Hillmen is Consultant in Clinical Haematology at Leeds Teaching Hospitals NHS Trust and Honorary Professor of Haematology at the University of Leeds. He is the clinical lead for the FLAIR trial and is setting up the new STATIC trial.

Prof. Hillmen covered the topic of Ibrutinib within the FLAIR trial and how the new STATIC trial would be looking at whether treatment may be paused or even stopped when good remission is achieved. In addition he spoke about CLL/SLL in general and answered questions sent in by the audience on Covid, vaccinations and new treatments.

There was also an inspirational talk by one of our trustees, **John Greensmyth**, who was **diagnosed with CLL 30 years ago**. It's a remarkable and life-enhancing story. Don't miss it!

If you missed the webinar, or would like to watch again, you can find it on our website here: https://www.cllsupport.org.uk/news-events/conference-reports/



Covid-19 update

Covid is still very much with us, and we will continue to try to keep you up to date with the latest developments that affect our members.

A "roadmap" for easing Covid restrictions in England is in place by the UK government. A reminder of where we are at present:

29 March Six people or two households allowed to meet outdoors	Key dates for lockdown easing in England:
Outdoor sports facilities open, organised sport allowed	
Travel outside local area allowed	
• Step two: 12 April* Non-essential retail and personal care open	
Hospitality outdoors open	
Indoor leisure eg gyms, swimming pools open	
Self-contained holiday accommodation open	
• Step three: 17 May* Outdoors most social contact rules lifted	
Six people or two households can meet indoors	
Indoor hospitality and hotels open	
• Step four: 21 June* All legal limits on social contact removed	

Hope to reopen final closed sectors of the economy

*Earliest possible date Source: GOV.UK

BBC

Please note that there are different rules for each of the devolved nations and you can find more information here:

Scotland: https://www.gov.scot/ Full details are shown under the 'Strategic Framework' heading on this page Wales: <u>Coronavirus (COVID-19) | Topic | GOV.WALES</u>

Northern Ireland: https://www.nidirect.gov.uk/campaigns/coronavirus-covid-19

These regulations are subject to change by the individual nations concerned.

Clinically vulnerable people are still advised to shield until 31 March 2021



Relaxation of shielding

Many of our members have been shielding, and recently it was confirmed that shielding in England will once again be paused from the 31st of March.

The reason for this is that there has been a reduction in cases and the majority of the 'at risk' groups have been vaccinated. There is an indication that some forms of support will remain, such as priority shopping delivery slots.

However, we are concerned about the logic of shielding ending on this date and we would urge members to think carefully about how they can still protect themselves beyond 31 March.

Vaccinations are not fully protective, especially in blood cancer patients, and new, more infectious variations of Covid-19 present additional problems.

Shielding is, and always has been, voluntary, so there is no compulsion to continue to shield. However, precautions such as handwashing, masks and social distancing are still vitally important for CLL and SLL patients.



Vaccines

We've received lots of gueries about the vaccines which are now being distributed. We have, therefore, tried to answer these as far as possible.

You can find answers to many of your questions about vaccines on our website here:

https://www.cllsupport.org.uk/covid-vaccine-qa/

We encourage all members and their families to have a vaccination if offered.

However, we know the effectiveness of vaccines may vary for people with compromised immune systems, such as CLL patients.

Marc Auckland is working with the **Blood Cancer Alliance** to lobby the government to create a UK wide monitoring programme. We have supported a letter to the Rt Hon Matt Hancock MP Secretary of State for Health and Social Care, and you can find this letter here:

The+Rt+Hon+Matt+Hancock+MP+-+JCVI+letter+11.03.21.pdf (squarespace.com)

eukaemia Care.

Still on the subject of vaccinations, there will be an informative webinar coming up shortly:

Webinar on "Next steps with shielding and vaccination for COVID-19" Our sister charity Leukaemia Care will be running a webinar on 30 March 2021 starting at 3.30

More details and registration can be found here:

https://us02web.zoom.us/webinar/register/WN rp5koCMISOWgyNYdpoA8wQ



Another joint initiative

We have joined 46 other cancer charities to speak with **One Cancer Voice** on what we need from UK Governments and the NHS to plot a route out of the pandemic and towards world-leading cancer services.

Our statement is not about looking backwards, it's about recognising the herculean efforts of those on the front line and looking forwards. It's about recognising the needs of people affected by cancer and those that care for them. It's about setting out, collectively, what needs to happen to get our shared ambitions to beat cancer back on track.

There is an estimated backlog of cancer cases of over 40,000 people across the UK who should have started cancer treatment in 2020. The majority of these are people who are living with cancer but don't know it.

You can find the full statement, together with the list of supporting charities here: ocv statement feb 2021 final 002.pdf (cancerresearchuk.org)



Important survey finishing soon

We have been asked by CLL specialists to help them gather more information about the spread and impact of the Covid-19 virus on CLL patients. This is the fourth in a series of surveys to try to find out how Covid-19 is affecting patients.

Why is this important?

Consultants need this information to enable them to make informed decisions, and we have agreed to help, along with our sister charity Leukaemia Care. We have now been living with the COVID-19 pandemic for over 12 months and it continues to have an impact on the lives of CLL patients, their families and supporters. We would like to better understand the impact of this latest stage of the pandemic and changes to guidelines.

How you can help

Please can you answer a handful of further questions. This is an initiative from the UK CLL Forum the specialist clinical community, in collaboration with two charities, CLL Support and Leukaemia Care.

How will this data be used?

This survey has been created by CLL Support, Leukaemia Care and the UK CLL Forum. Leukaemia Care is the data controller. Data collated and anonymised from this survey will be shared with CLL Support and the UK CLL Forum but will <u>not</u> be used to send further marketing information to you. You will not be added to any databases and if you wish to be placed on charity mailing lists, you will need to contact the charities involved directly.

In the last section, there is an option to submit your personal data. By submitting this data, you agree that you are happy to be further contacted about the contents of this survey ONLY. For more information about anything about this data collection, please email advocacy@leukaemiacare.org.uk in the first instance.

What we would like you to do

We are asking everyone to take part in the survey, which will be open until the end of March. If you feel you have the virus we would particularly like your input, but the survey is open to all CLL and SLL patients.

We would be delighted if you feel able to help. Please use this link to the survey, which will give you more information.

CLL and COVID-19: Closing questions (google.com)

Completing the survey will take only a few minutes, but will provide valuable information for our doctors.

Even if you filled in the previous surveys, it is still important for you to complete this follow-up as it will help consultants judge how things are changing over time.

Thank you for your help, it's really appreciated and will benefit CLL and SLL patients.

A patient's story—and an amazing fundraising effort!







Hi my name is Cormac Davey. I am 54 and currently live with my Canadian Wife in Swindon, Wiltshire.

Just over a year ago, I was given an unexpected cancer diagnosis, specifically chronic lymphocytic leukaemia (CLL). Right now I am fit and well and currently have no physical symptoms and thus do not require any treatment. I was diagnosed at an exceptionally early stage and am in good hands with my local NHS consultant. I have also benefited as a participant in an Oxford University research project.

I have always prioritised a healthy lifestyle. I work as an expedition leader and work with adults and youth in the great outdoors. So I am hiking / walking outside within the UK and overseas a lot. I count myself as extremely lucky with my work. I have a small business and Podcast called The Living Project. At The Living Project we provide the opportunity for adults and young people to explore a therapeutic human journey with the wild.

You can find out more via the website: http://www.thelivingproject.life/

The current limitations on travel, posed by the UK lockdowns, led me to explore my local running trails. I found that as I've got stronger, I have been able to run further on more remote terrain around the Marlborough Downs and the Ridgeway.

Recently, I have been motivated to set my sights even further and have committed to a formidable challenge. I aim to complete a 100K ultra-run, along the ancient Ridgeway path (finishing at the Avebury Stone Circle), on the 5/6th June 2021. I would like to complete the route in under 24hours.

The Ridgeway

I have a deep connection to this landscape and hope to have the encouragement and support of family and friends throughout my training and on the day itself.

I'd also like to raise awareness and funds for CLL Support in your mission to empower CLL patients, their families and supporters through education and current information.

My fundraising goal is a minimum of £550, as I will be celebrating my fifty-fifth birthday this June.

Thanks for taking the time to read and please consider supporting me in anyway you can. I will post updates on my training and let you know how you can monitor my progress on race day.

I have set up a Just Giving Page and this is the link:

https://www.justgiving.com/fundraising/cormacultrachallenge

Donating through Just Giving is simple, fast and totally secure.

Much love

Cormac

We would like to thank Cormac for his tremendous efforts on our behalf, and wish him luck in his challenge. And to all our other fundraisers, a huge thank you. Without you we couldn't carry on our work on behalf of CLL patients.

If you have any fund-raising plans—whatever they are—we would love to hear from you.



Looking after your mental health

The current situation imposes new levels of stress for many people.

As the survey results from the recent UKCLL Forum show, there is a substantial number of patients suffering from varying degrees of mental anxiety, and this is something we would like to help with.

We are developing on our website a number of resources of help and advice about mental well being. The first of which is a very simple series of suggestions and tips for coping with the current situation, known as 'STAND'. This has been prepared by Julie Tanner, a counsellor in mental health. You can find it here:

https://www.cllsupport.org.uk/information-support/support-for-you/

You will also find some tips from Katie Perry, who is a family therapist and psychologist.

We will be posting more resources over time, and if there are any aspects you would like us to cover, please do ask. Ideas and requests can be sent to: coordinator@cllsupport.org.uk

Remember if you need to speak to someone you can always call our helpline: 0800 977 4396



Our new free Will-writing service.

Thank you to all our members who have taken advantage of this service. You are truly helping us to make a difference.

Currently, during the lockdown, all solicitor consultations are taking place online.

We understand that the decision to write a will can be a delicate topic and must be handled sensitively. But it would be wonderful if you could read on before deciding if this is something you can 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 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 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: CLL-Legacy-leaflet.pdf (cllsupport.org.uk)

Don't forget to smile! Even through all the problems!

Our fundraising activities have necessarily had to be cut short for the next few months at least. However, we still need to try to generate an income and one relatively painless way of helping us, and if you ever use **Amazon**, is to log on to the **Amazon Smile** site instead of the usual one. It's precisely the same, and doesn't cost you any more, but CLL Support will receive a small percentage of whatever you spend. The first time you log on you will be asked to nominate your chosen charity and CLL Support will pop up. With many of us having to self isolate, DVD boxed sets will be an essential requirement, so if you decide to buy from Amazon, just log on the Smile!

We only receive a small amount (£0.01 per £ spent), but it soon adds up so please do use it! In fact, to date we've received £836.00.

HealthUnlocked

smile amazon couk

HealthUnlocked

HealthUnlocked is our international online Forum where you'll find advice and the latest information on CLL and the problems experienced by fellow sufferers. There are over 15,000 members, and the site is moderated by CLL Support administrators and volunteers to ensure the information is up to date and accurate. This applies particularly to information on CoV-19, where reliable information is so important. You don't need to participate unless you want to ask a question, but if you do you will receive a warm welcome from fellow CLL sufferers. Why not have a look at: https://healthunlocked.com/

We would like to pay special tribute to all our admins and volunteers, who are working exceptionally hard at the moment. They all have experience of CLL and are doing an amazing job. Thankyou!



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 nearly always do.

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. Contact us at: coordinator@cllsupport.org.uk

We look forward to hearing from you.

Until Next Time

Be sure to follow us on <u>Twitter</u>, <u>Facebook</u>, and <u>HealthUnlocked</u> for all the latest information and discussion on CLL. Remember, every post you like, share and retweet helps to raise our profile, allowing other people living with CLL to discover us. CLL Support is the only UK charity dedicated to providing education, support, and advocacy to help empower people living with CLL.