



Our top stories in this newsletter



Latest Corona Virus Update



New webinar with Dr Ben Kennedy



Survey update



A message from Marc Auckland, CLL Support Chair.

Welcome to this edition of our newsletter.

Our mission from the first days of the charity has been to inform, support and connect. These words have never been more important than today. This is a truly anxious time for everyone, but particularly for those of us who have health concerns that make us more vulnerable to infection.

I want to assure all our members that our trustees are working hard to provide support and trusted information whether you are newly diagnosed or have been living with CLL for some time. We are working with our sister charities, Leukaemia Care, Lymphoma Action, Blood Cancer UK as well as the NHS, British Cancer, Alliance, and the UK CLL Forum to bring you the latest reliable information. We are also pressing Government on matters that concern us, such as the relaxation of shielding for extremely vulnerable patients.

Our latest webinar, details of which you can find below, is an effort to reach out to members in a new way. I am very pleased to say that these events have been hugely popular, and the feedback has been very positive. We are planning more in the future.

Finally, a request. We work with pharmaceutical companies to help ensure that the best treatments, trials, and support are available to CLL patients and their families, and this is a core part of our work.

The impact of COVID19 has raised the importance of ensuring that those companies providing treatments really understand the issues patients face and act swiftly on their needs.

For this reason, in partnership with Janssens and other patient charities we developed a survey to give CLL patients and their partners the opportunity to say what they would like these companies to focus on. The results of this patient survey will be used to prioritise the efforts of the company and the patient groups who work with them, including CLL Support.

Please will you spare a 15 minutes to complete the survey here: https://surveys.w3dl-ask.com/survey/selfserve/2113/200102?list=1

This will help us to ensure pharmaceutical companies focus on patient needs. Thankyou.

Please stay safe and well. Remember that we are here to support you, so please don't hesitate to contact us if you need help.

Marc Auckland

Chair of trustees.



Covid-19 update

Government guidance on Covid-19

Covid-19 has changed all our lives and is likely to continue to do so for some time yet. In a fast-moving landscape, we try to keep up to date with developments in research, treatment, and government decisions. You can find the latest government advice on our website here https://www.cllsupport.org.uk/latest-government-advice-on-covid-19-issued-22-june-2020/ and this is updated constantly.

Shielding

Shielding is to be 'paused' from 1 August in England, Northern Ireland, and Scotland if the Covid-19 infection rate remains low. It will be paused in Wales from 16 August. We are concerned about this. Shielding currently treats everyone, including people with blood cancer, as a single group, but we know that there are differences in their risk which makes blood cancer patients more susceptible to the virus. We are joining with Blood Cancer UK to lobby the government for a more nuanced approach which will recognise the special vulnerability of blood cancer patients to infection.

Choosing to shield, and how you shield, is a personal decision, affected by more than just your level of risk. There are many things that may affect your decisions about shielding:

- your understanding of your level of risk
• the mental and practical impact of shielding
• your personal feelings about what risks you are willing to take.

We recommend contacting your medical team to get their advice about how you should treat this relaxation of shielding, as it will affect patients differently according to their individual medical condition and where they are on their CLL journey.



The relaxation of shielding is a particular worry for patients who are being asked to return to work, and we are joining with Blood cancer UK in their 'Save Our Shielders' campaign. This asks patients to write to their MP for help in extending the furlough scheme after August 1. You can find details here: https://bloodcancer.org.uk/get-involved/support-our-campaigns/save-our-shielders/



New vaccines

Encouragingly, there are currently over 100 Covid-19 vaccines in development and trial. A vaccine is considered to be the only way in which long term suppression of the virus can be achieved.

One of the leading candidates has been developed by Oxford University and is in trial in the UK, America, Brazil and South Africa. Results of the phase one and two trials show that it is safe and phase three trials now underway will demonstrate its effectiveness. Our interview with Prof Pollard, below, gives more information on the development of the vaccine and how the trial is going. It's notable that this vaccine can be given to CLL patients.

It is hoped, but not certain, that the vaccine will be available before the end of the year.

Other vaccines in trial and showing promise include ones from Biontech-Pfizer and Valneva, which use different methods.

Treatments

The search is on to find if existing drugs can help in the treatment of Covid-19 patients. Britain's Recovery trial is leading the way, and there are some interesting developments.

- The University of Southampton has tested a drug, interferon beta, on a small number of patients. This showed that 79% were less likely to need ventilation. They were also twice as likely to recover and return to a normal life.
• Remdesivir, an anti-viral shows some effectivity.
• Dexamethasone, a steroid, has been shown to have reduced deaths by a third in Covid-19 patients on ventilators.
• Convalescent Plasma - plasma taken from Covid-19 patients - is being tested to see if it protects new patients.
• Azithromycin, an antibiotic, and an antibody called tocilizumab are also being tested.

It is important to note that it is still too early to say if any of these possible treatments will prove to be wholly successful, and they have not been peer-reviewed. Further research is needed, but it's encouraging that so much work is being done to try to find effective treatments.

We will keep you up to date with any changes in advice, so check our website regularly.



Webinar with Dr Kennedy, Prof Pollard and Rory Williams

A few days ago, we hosted our second webinar and we were very pleased to have a distinguished line up of guest speakers.

Dr Ben Kennedy, consultant haematologist at Leicester Royal Infirmary, gave a fascinating and informative talk about CLL in the time of Covid-19. Well worth watching.

Prof Andrew Pollard, who is Chief Adviser to the government on vaccines and Chief Investigator on the Oxford vaccine trial that has been so much in the news, gave us an update on the development of the vaccine. The vaccine may well be a crucial factor in helping us all to get back to a normal life.

Rory Williams, a CLL Support member, and his wife Celia, spoke about his experience of contracting Covid-19 and coming through. It's a compelling and encouraging story.

If you missed the webinar, you can still see the talks here.

https://www.cllsupport.org.uk/conference-reports/cll-support-webinar-16-july/

Our next webinar just announced!

Our next webinar is planned for 1 September 2020. Put a note in your diary now! More details available soon!



Leukaemia Care will be hosting a new webinar:

'Navigating changes as shielding pauses'

Date: 4th August

Time: 2.30 pm

Guest panel:

Prof Chris Fegan (University Hospital Wales), Prof Mhairi Copeland (Glasgow University) and Prof Mary Frances McMullin (Queen's University Belfast)

As broad shielding guidance is paused for the group of clinically vulnerable patients across the UK, Leukaemia Care are hosting this webinar with leading haematologists from different specialisms to aid patients and their families into next steps. The aim of this session is to aid patients build their confidence with risk mitigation and carrying out activities in this new landscape. This session will end with a discussion and Q&A.

This webinar will be available online via Zoom and on Leukaemia Care's Facebook Page.

Register your attendance via Zoom here

https://us02web.zoom.us/join/register/WN-0zseDKzR-S_hwpVOWdbxw

Or tune in to Leukaemia Care on Facebook on Tuesday 4th August at 2:30pm



The big survey

A huge thank you to everyone who completed our last survey, and this is already providing essential information to help CLL consultants.

This was carried out in conjunction with the UK CLL Forum and Leukaemia Care, and the results are proving to be extremely helpful to clinicians in their forward planning for patients as well as ourselves to understand patient needs.

A total of 2762 people completed the survey and the results are published on our website here: https://www.cllsupport.org.uk/covid-19-uk-cll-patient-experience-survey-3-interim-report/

This has been a major and very important survey and a summary of the findings to date are:

- This patient population are well-educated on shielding, but many are unable to shield strictly
• Restrictions and barriers to shielding are either mental, emotional, or practical
• Patients feel that the NHS are doing a good job (in terms of their ongoing CLL care and/or treatment)
• There has been an overall reduction in patients' level of worry about the outbreak
• There has been a slight reduction in patients who are worrying about their own health at this moment in time

Despite these reductions in worries, approximately 1 in 10 patients are expressing a wish and need for access to psychological support to cope with shielding and the impact of the pandemic

We expect patients to have increased anxiety about attending clinics and GP surgeries as shielding is relaxed and we may hold another survey to investigate this.

We will shortly publish the findings of the three surveys combined, which will show how reactions to Covid-19 have varied over time.

We would like to thank everyone involved in the three surveys.



Under 60 club

A record of lockdown

Lockdown has been a difficult experience for many people, and we asked for some thoughts from Club members about being in lockdown. Matt Gibson, whose idea it was, has collected some of these. You can find them on the new Under 60 Club page here.

We think you will find them an interesting record of how members have coped.

If you would like to contribute your personal experience, we would love to hear from you. Please contact Norah in the first instance: norah.grant@cllsupport.org.uk

More news

The Under 60 CLL Walking WhatsApp Group has a walk planned in South Wales in September and one around Graham Water in October. A member of this group suggests that CLL stands for Clearly Loving Life!

The Couch to 5km group is battling the mid-summer, pandemic doldrums and pushing themselves to keep running! Bravo!

The Under 60 Club is always accepting new members. Contact Norah at norah.grant@cllsupport.org.uk

We want to hear about your CLL journey, and you'll be supported by others on a similar path. Share your thoughts on stepping down from shielding. We are stronger together. Norah.grant@cllsupport.org.uk



Back to work

From 1st August, those who have been shielding are being invited to transition back into work when it is safe to do so and as long as the workplace is Covid-safe.

Our sister charity Leukaemia Care has put together some information with all the advice and guidance you may need if you are thinking about returning to work, and you can find it here https://www.leukaemiacare.org.uk/support-and-information/latest-from-leukaemia-care/blog/returning-to-work-after-shielding?mc_cid=2bf6705c618mc_eid=ffe62bf293

The thought of returning to work after shielding is likely to affect you in different ways. You may feel relief in being able to go back to a sense of normality and to see your work colleagues, or you may feel anxious and apprehensive to go into the workplace again. Whatever you are feeling, remember that this is completely okay.

Every workplace is different: some involve working indoors all the time, some are mainly outside. The number of people you will come into contact with will also vary. Therefore, the steps is needed to make a workplace COVID-safe will also vary. As a result, it is difficult for us to provide specific advice for everyone.

This guide is designed to help you find the right information for your specific circumstances.

A patient's lockdown story - something completely different!

I am 58 years old, and have been a member of the CLLSA for some 9/10 years ever since I had to go to Southampton General Hospital in 2011 for FCR for my CLL which had got worse since being diagnosed in October 2019 aged 47.

I live in Guernsey, Channel Islands, so I had to fly there, and my local Health Department paid for an apartment in Southampton for 6 months while I underwent treatment. After the treatment was finished, I achieved MRD and had 3.5 years of normal health, as I have been an airline pilot for the last 30 years, and I had to stop flying again when I was put on Ibrutinib in early 2016.

After some 18 months, I got my stringent pilot's Class 1 medical back and have been fine since with my white cell count just a few points above normal. I was told by my Southampton Consultant Haematologist last week on the phone for my six-monthly check-up, that the big decision for Ibrutinib is after 6 years. He has had some patients on the drug after this time but not a many. I will have to see if I remain on it or change to Venetaclax - a different form of targeted therapy for CLL with possibly less side effects.

During lock down, I decided to do something I had wanted to do for 35/40 years since I worked as a trainee tape operator at Mickey Most's RAK Recording Studios in London in 1979: I wanted to actually finish, record, mix and release one of my own songs!

I have always played the piano/keyboards (and used to play the guitar and bass guitar!), and have written hundreds of tunes, melodies, and songs - but never ever finished them for whatever reason.

So at the start of April in lock-down, I decided to write and record a track - all on my iPad; it materialised as I went along - not really planned - and was finished in mid-May; I would have finished earlier, but I have a 2.5 year old son who takes up a lot of my time, as well as doing some work.

I then got an Australian YouTuber who does many videos for recording on iPad and the software I use as the recording studio, and he really liked it. He encouraged me to finish it, and I learnt a lot from his videos in how to actually do this! He even played it on his YouTube channel of over 55,000 subscribers.

I have been told it has a touch of the Pet Shop boys in it, which was strange as I never really liked them!

My song is called 'Lockdown' and is available for download from all the major worldwide music retail platforms such as Spotify, Amazon, Google Play, Deezer, Apple Music and iTunes etc. My artist name for this released track is 'Timobeanie' - should anyone want to download it.

Anyone can listen to my track here on Soundcloud: https://soundcloud.com/tim-osborne-564621297/lockdown-bandlab-remix

I made use of the lock down here in Guernsey, and I am now writing and recording my next track Watch this space!

Looking after your mental health

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

As the survey results above 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 sources 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/

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

An appeal

In common with many charities, our income has grown to a halt. We survive only because of the generosity of members who raise funds for us by such things as running, climbing, sky-diving, trekking, as well as from less taxing activities such as coffee mornings and baking cakes.

Unfortunately, all of these activities have stopped in the present pandemic, and so has much of our income. And this is at a time when demand for our help has increased enormously.

We are fortunate that the trustees have always been careful to make sure that we have good financial reserves to enable us to continue our work in difficult circumstances like these. However, we don't know how long the present problems are likely to last.

For this reason, we are seeking your help, if you feel able to.

We would like you to consider making a regular donation to the charity.

We do appreciate that this is not possible for everyone. However, if you feel you can help us with a regular donation, we would be enormously grateful. It would help us to maintain our efforts to help CLL patients across all our activities.

It's simple to do, just check out the page on our website here:

https://www.cllsupport.org.uk/donate/

Thank you.

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!

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, but if you do not 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. The 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:

We look forward to hearing from you.

Until Next Time

Be sure to follow us on Twitter, Facebook, and HealthUnlocked 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.