



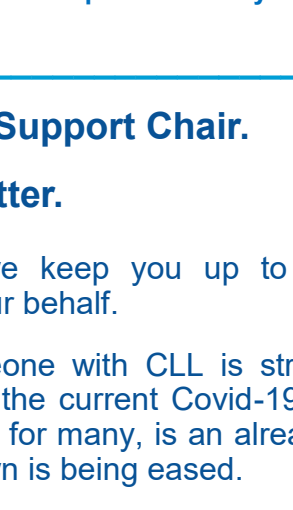
Our top stories in this newsletter



Latest Coronavirus Update



New webinar with Dr Choudhuri



A patient's story

A message from Marc Auckland, CLL Support Chair.

Welcome to this edition of our newsletter.

Welcome to our latest newsletter, where we keep you up to date with information about CLL, and our activities on your behalf.

We know that living with or supporting someone with CLL is stressful and brings its own challenges. We also know that the current Covid-19 crisis has only added to the worry and confusion of what, for many, is an already difficult situation. This is especially the case as lockdown is being eased.

On behalf of the trustees, I want to assure you that we are here for you and that you can still access our information and support. Our helpline is available if you need to get in touch (0800 9774396). If you have any questions or concerns, whether Covid-19 related or not, please don't hesitate to pick up the phone. I hope you will join us for our regular webinars which will bring you up to date information on CLL and the coronavirus.

We are committed to providing you with the support you need and hope that you will continue to help us, as you have done over the years.

We want to make sure that no one must face CLL alone and our trustees, all of whom have personal experience of CLL, are committed to that end.

Finally, if you have any suggestions or ideas we could develop to benefit members, please do drop me an email. If you are interested in becoming a trustee which would involve around 4 to 5 days work a month, or if you can only spare a few hours a month, please contact me. Just indicate the skills or experience you can bring or the area of support that interests you.

I wish you well and hope you and your family stay safe.

Marc Auckland

Chair of trustees

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Covid-19 update

Figures for coronavirus show that we are now getting an increase in the number of cases to about 3000 per day in England but the number of deaths seems to be levelling off. Other regions of the UK are also experiencing increases in cases and the need for vigilance is still with us.

There are pockets of higher infections around the country and if you would like to check the latest information for your area a good source is here: https://www.bbc.co.uk/news/uk-51768274

The good news is that researchers all over the world and especially the UK have developed vaccines which are undergoing trials which seem to show some very positive results.

Therapies have been developed which can be used for patients who get very ill such as the steroids dexamethasone and recently hydrocortisone, and inhaled interferons - again the studies for these trials have mainly been carried out in the UK.

In the last 6 months much has been learnt about this virus and the progress the scientific and medical community has made will help to tackle the second wave that will inevitably come this winter.

The flu virus, of course, will make identifying the coronavirus more difficult as they have very similar symptoms.

For this reason, it is important that all CLL patients and their families receive the flu vaccination as soon as possible. Some GPs are already making appointments for September, and Boots chemists and other high street chemists are doing the same.

Vaccine

We understand that the Oxford vaccine, which is one of the front runners in the world-wide search for a viable vaccine, is still on track, although it may not be available until the end of the year at the earliest. It is currently in advanced trials in the UK, Brazil, South Africa and the USA and the target number of people enrolled into the trial has almost been reached. The trial was recently paused because of one patient becoming ill, but on investigation, this was found to be unconnected with the vaccine, and the trial has restarted.

An interesting alternative from Imperial College London is in development and uses modified ribonucleic acid (RNA) to create immunity, whilst Cambridge University, jointly with University Hospital Southampton, are developing computer designed proteins which can be delivered through the skin by a jet of air. It is hoped that trials with these will start soon.

There are very encouraging signs that a viable vaccine will be available, but the timing is, as yet, uncertain.

Why is an extended trial necessary?

You may have heard that some vaccines and treatments for Covid-19 have been fast-tracked by other countries without extended trials. This is very unlikely to be the case in the UK as the purpose of trials is to test the safety and effectiveness of the vaccine or treatment. The rules are extremely strict to avoid unanticipated severe side effects, which have occurred in the past when safeguards were abandoned. Often, these side effects do not become apparent until some time after the initial vaccination.

Latest Government advice.

Lockdown and shielding advice was eased across England from 18 August, Wales from 16 August, Northern Ireland from 31 July and Scotland from 27 August. Different advice and conditions apply in each country and the relevant details can be found as follows:

England: https://www.gov.uk/search/all?keywords=extremely+vulnerable+in+covid&order=relevance

Scotland: https://www.gov.scot/publications/coronavirus-covid-19-phase-3-staying-safe-and-protecting-others/

Wales: https://gov.wales/people-extremely-vulnerable-covid-19-who-have-been-shielding-facts

Northern Ireland: https://www.nidirect.gov.uk/articles/coronavirus-covid-19-pausing-shielding-extremely-vulnerable-people

Our advice to all CLL patients remains the same: you should still take extra care; keep strict social distancing as far as possible; have close contact only with those people within your 'bubbles'; wear face masks when in confined spaces; wash hands frequently.

The level of risk each individual will be prepared to take will vary from person to person, but you should be aware that CLL patients are extremely vulnerable to the Covid virus.

Webinar with Dr Satarupa Choudhuri

Our third webinar in the current series took place on 1st September and was with Dr Satarupa Choudhuri, who is Consultant Haematologist at the Royal Oldham Hospital and Honorary Senior Lecturer at Manchester Metropolitan University.

Dr Choudhuri, in a wide-ranging talk, discussed the role of the District General Hospital in the treatment of CLL patients, and the problems associated with the changes made because of Covid-19.

There was also a fascinating patient's story from one of our under-60 club members, David Martin, and an update from Marc Auckland about the work of CLL Support.

You can find the full webinar on our website here:

Blood Cancer Awareness Month

September is Blood Cancer Awareness Month and we will be joining our sister blood cancer charities in doing everything we can to raise awareness of blood cancer. It's a pity that, because of Covid-19, all major events have been cancelled. Instead, people are asked to do whatever they can to tell their stories and we would love to hear from you about your CLL journey. If you have anything you would like to contribute, please contact us at coordinator@cllsupport.org.uk

You can also help by:

- Raising awareness in social media by 'liking' and sharing our posts on Facebook, Twitter and WhatsApp.
- Making a regular gift to CLL Support. By doing so you will enable us to continue our work and help us make a real difference for patients and their families, now and in the future.

A patient's story.

Managing treatment change in time of Covid 19

One of our Trustees, John Greensmyth, was faced with a treatment change dilemma soon after going into Shielding lockdown, here is his own account of his experiences.

I started Ibrutinib in October 2014 and was effectively living proof of "Living well with CLL", however last December I started getting a series of chest infections which didn't really respond all that well to medication. We also noticed my blood counts started to move in the wrong direction and in March this year it was clear that Ibrutinib was no longer working for me and a big decision was imminent.

I've had CLL for 30 years (I'm 62 years old) and faced some big decisions during that time but at the start of lockdown I can honestly admit that I was more scared of the risks of Covid -19 than I ever was with my CLL. It's probably irrational I know, as we have little control over our CLL, but Covid-19 just seemed to have that aura of an unknown invisible killer about it.

I've been lucky to have had the same Haematologist for the last 20+ years so we can have a good discussion whenever I've reached a milestone treatment point. My bloods displayed a clear deteriorating trend but possibly not enough to warrant immediate action. Venetoclax was my only real option, however any delay would just postpone the inevitable decision and I might not be as well at that stage. In the end I opted to go ahead with the changeover to Venetoclax.

I started the process in the first week in May. The main issue is the initial phase of the treatment as there is a high risk of Tumor Lysis Syndrome - TLS (rapid cell breakdown and impact on kidneys as the system flushes those cells out). To counteract this oral Allopurinol is prescribed as well as the need to consume large quantities of water on a daily basis - I felt like a water-filled balloon at times!! A baseline blood test is done on a Monday and I commenced with the smallest dose of 10mg on Tuesday morning with a blood test 6 hrs later.

Another blood test at 24hrs and decision to proceed is taken at that time, but in my case it was all stop as my kidneys were displaying warning signals, not TLS but a high risk of TLS if we continued. I wasn't too pleased at this stage as I now needed to wait a week and then re-start treatment as an in-patient where I could be monitored more closely. On reflection this was the best method. Any Covid risk fears I had were reduced by the reassurances I received about ward separation from the Covid treating area of the hospital. I was placed on an IV drip alternative to Allopurinol (Rasburicase) and it was more effective, I was also on IV fluids, so hydration wasn't an issue. We successfully completed stage one and I was discharged after two nights. The daily dose ramps up in steps - effectively doubling each week and after that everything was done on an out-patient basis. I would drive the 30 miles from home, park right outside the ward entrance, have bloods taken in an almost deserted, collect meds and go straight back home to continue shielding. I had to take a week's break at the 50mg step just to rest the kidneys but all went well after the initial hiccup. I'm now at full dose (400mg) and my bloods have returned to "my normal" - in fact they showed a clear improvement soon after the initial dose which really surprised me.

I was monitored weekly for two months after reaching the full daily dose. I've had little or no side effects bar some tingling in my fingertips if I hold a book or my iPad in bed at night time. I'm now (August) on monthly blood tests and a follow-up telephone appointment. My Haemoglobin levels have fully recovered so I'm now back on my road bike and regaining my lost fitness due to shielding inactivity.

In conclusion the prospect of having to change was somewhat daunting but the change wasn't and I hope Venetoclax works for me as long as (or longer than!) Ibrutinib. It just underpins the need for pharmaceutical research into new targeted therapies as an alternative to chemotherapy.

Live well with CLL, Regards, John

A reminder- book your flu jab!

We've mentioned this earlier in this newsletter, but:

It's even more important this year to make sure you have a vaccination for flu. G.P.s are already starting to book appointments and as there is sure to be a big demand, we suggest you contact your doctor now. As an alternative, most chemists, including Boots, offer vaccinations on the NHS.

There is some research that having the vaccination in the morning provides greater protection, although this may vary from person to person, and the exact mechanism is not clearly understood at present.

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 on September 19 and one around Graham Water in October. Interested? Contact gailweigman@cllsupport.org.uk

The Couch to 5km group is battling the mid-winter, pandemic doldrums and pushing themselves to be running! By the time this newsletter is published they will have done a 5k run - all separately but together in spirit!!

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

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 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—and a new way you can help

In common with many charities, our income has ground 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. Two of the ways you may be able to help:

Our new free Will-writing service.

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 written 'simple' Wills (or mirror Wills for a couple) entirely free of charge and valid 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 here:

Could you to consider making a regular donation to the charity, however small?

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.

A warm welcome to Anthea Holland.

Anthea has joined us in a newly created post of Associate Trustee. She is a retired GP and says: "I enjoy having the time to give something back to organisations that share my values".

She has a Labrador, Molly, and enjoys choral singing. About her CLL, Anthea says: "I don't wish to be defined through my illness, although having CLL has taught me a lot. While I would never have wished to have this diagnosis in a way it has enriched my life and taught me never to take it for granted".

We look forward to working with Anthea.

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. 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 give 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: coordinator@cllsupport.org.uk

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.

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