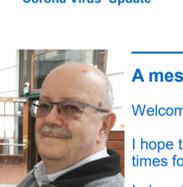
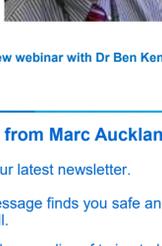




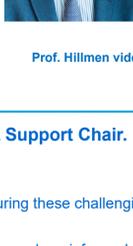
## Our top stories in this newsletter



Corona Virus Update



New webinar with Dr Ben Kennedy



Prof. Hillmen video

## A message from Marc Auckland, CLL Support Chair.

Welcome to our latest newsletter.

I hope this message finds you safe and well during these challenging times for us all.

In keeping with our policy of trying to keep our members informed of developments in the Covid-19 situation, we are doing our best to make these newsletters more frequent. This is, we believe, even more relevant as the lockdown is eased progressively. There is understandably much confusion and also anxiety for many patients about what this means for them and how they should react. For this reason the latest UK Government announcement regarding the reduction of some restrictions is covered in full.

We cannot mount our usual and very popular conferences until at least next March, so we are instead inviting you to a series of webinars which will still have the top CLL consultants speaking and taking questions. All of these are free to attend, and will be uploaded onto our website soon afterwards. I am very pleased to say that our inaugural webinar was a great success, with over three times the number of attendees than we can cater for at our conferences.

As well as our own webinars, we are also working actively with Leukaemia Care and please see the details below of their next CLL webinar. They are proving to be extremely popular. We will keep you updated of all of these as they are scheduled, so please keep a look out for them.

Wishing you good fortune.

Marc Auckland

Chair, CLL Support.

## Covid-19 update

### Government guidance on Covid-19

On 22 June, the UK government issued new guidance covering a gradual reduction in lockdown measures.

These Guidelines are somewhat complex and so we have printed them in full on our website, together with a list of questions and answers which we think will be helpful. **Please note that this refers to the advice for England only and the devolved governments will be issuing their own guidance in due course. This will also be available on the website.**

For CLL patients, who are in the 'extremely vulnerable' category, the essential part of the guidelines is as follows:

**"The categorisation of 'clinically extremely vulnerable' will remain in place and people in this cohort should continue to follow the guidance specific to them, (as previously). After 1 August, we will continue to maintain the Shielded Patient List. We will monitor the virus continuously over the coming months and if it spreads too much, we may need to advise this group to shield again."**

The full advice can be found here: <https://www.cllsupport.org.uk/latest-government-advice-on-covid-19-issued-22-june-2020/>

Patients will naturally have a degree of anxiety after following strict shielding, and although the epidemic is greatly reduced, it will still be necessary to have a sensible degree of caution.

**Our advice remains strictly to maintain social distancing at all times, and wash hands frequently and thoroughly. If you do go out, wear a mask and protective gloves.**

These are very basic precautions and ultimately it will be up to each individual to assess what level of risk they are willing to accept, preferably after discussion with their consultant.

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

## Coronavirus webinar by Prof. Peter Hillmen

Earlier this month we hosted our first video question and answer session and we were delighted to welcome **Prof. Hillmen**, who is Consultant in Clinical Haematology at Leeds Teaching Hospitals, and NHS Trust Honorary Professor of Haematology at the University of Leeds.

During a wide-ranging talk about Covid-19 and the implications for CLL patients, Prof. Hillmen answered questions sent in by patients.

Our two other panelists were Paul Newis, who spoke eloquently about his Covid-19 experience as a CLL patient, and Marc Auckland, CLL Chair of trustees. Marc talked about the work we are doing on behalf of CLL patients.

The webinar can be found here: <https://www.cllsupport.org.uk/conference-reports/ccl-support-webinar-with-peter-hillmen-10-june-2020/>

We think you will find it interesting and informative. There will be regular webinars in the future in the absence of our conferences, so please keep a look out for them.

## Our next webinar just announced!

We are very pleased to announce that **Dr Ben Kennedy**, Consultant Haematologist, Leicester Royal Infirmary will be joining us on:

**Thursday 16 July at 1.00 pm**

Dr Kennedy will be speaking about developments in CLL treatment and how Covid-19 has affected clinical practice. There will be an opportunity to send in questions which Dr Kennedy will answer at the end of his talk.

Also joining us will be **Professor Andrew Pollard**, Government chief adviser on vaccines who is leading the **Oxford Vaccine** trial, which has been so much in the news. Prof. Pollard will give us an update on where the trial is at the moment and answer questions sent in by members.

**Register now [here](#), and make a note in your diary!!**

## CLL patients survive Covid-19!

The virus is particularly dangerous for anyone who has a damaged immune system, and this, of course, includes CLL patients. However, there is some good news because we are beginning to hear about patients who have caught Covid-19 and come through the experience. We will post their stories here and on our website. We are also planning to interview some of them on video.

### Our first story is from Sue Marshall. It begins:

I was diagnosed in 2010 and was treated with 5 rounds of Bendamustine/ Rituxin in 2014. I relapsed 18 months after treatment and started the Clarity trial in October 2016 – Ibrutinib and Venetoclax. I stayed on Ibrutinib at the end of the 2 year trial as I hadn't achieved MRD negative in my bone marrow. In June 2019 the trial was extended and I went back on Venetoclax which was due to finish in June 2020.

It all started quite innocently a week and a half before lockdown. Had a bit of a headache and an upset stomach. Felt much the same the next day. Took some paracetamol and fell asleep on the sofa. Saturday morning interestingly I felt quite a bit better and managed 15 minutes on my rebounder. By evening I didn't feel too good and took some paracetamol and went to bed. The next morning my temperature was 38 and I had awful diarrhoea which was what prompted me to ring the Christie hotline. They said to come in so they could assess me. They did all the normal 'obs' and blood tests and I stayed in overnight. The next morning a doctor arrived complete with mask, plastic apron and rubber gloves and said they were going to swab me for Covid although they thought it was extremely unlikely that I'd got it. I didn't feel too bad and was eventually allowed home later that day. Fell asleep on the sofa, woke feeling dreadful, took paracetamol and went to bed. The next morning a doctor rang to say I had tested positive and they'd really like me to go back in again for a chest x ray and heart monitor. At that point in time I really wasn't feeling very well and just wanted to stay in bed. I pulled clothes over my pyjamas and reluctantly set off back to the hospital.

To read more, go to Sue's full story [here](#).

## Small things, big difference!

We collaborated with three of our sister charities and the pharmaceutical company Abbvie to produce this small booklet.

It contains the inspiring thoughts and experiences of a variety of CLL patients and how they are dealing with the condition.

**We think you may find it an uplifting read, especially in the current difficult circumstances.**

The booklet can be downloaded from our website: <https://www.cllsupport.org.uk/small-things-big-difference-inspirational-booklet/>

## 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 the third survey we 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 now published on our website here: <https://www.cllsupport.org.uk/covid-19-uk-cll-patient-experience-survey-3-interim-report/>

This has brought a major and very important survey. Amongst other things, it has highlighted the concerns and anxieties of patients and their families during the lock-down. Just one example is the answer to this question:

5) Do you feel you are coping well mentally and emotionally as a result of shielding against COVID-19?  
1,067 responses



This is a revealing insight into how our members are coping and we are finding ways to try to help this group. One example of this is the *Small things big difference* booklet noted above. It's well worth checking out.

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

**The full survey results can be found here:**

<https://www.cllsupport.org.uk/covid-19-uk-cll-patient-experience-survey-3-interim-report/>

## Under 60 club

**A new landmark! The club has reached 100 members, which, as it was only started only a year ago, is a great achievement. Thank you to everyone for their hard work, and especially to our trustee, Norah Grant who's original idea it was to start the Club.**

Norah says:

"I would like to thank all the members of the Under 60 Group for all of the support they give. It's been an honour knowing you all, especially during shielding.

Gail Wiegman, who runs the helpline has been an invaluable co-administrator. She has now started a an Under 60 CLL Walking WhatsApp group, and a Couch to 5 km running group! We are getting fit! Our one year anniversary and 100 members!! Founding members Matt Gibson and Paul Glinn joined the team to help keep our positive, supportive and fun group going strong."

**And there's more:**

Following a suggestion from member Matt Gibson, we are very keen to mark the unique circumstances we have all faced in recent weeks and months through the creation of a "Memories of Shielding" project.

### How would this work?

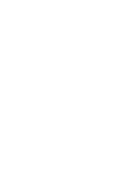
**Anyone who has a photo or thoughts about life during Covid-19 and how it has affected you, we would love to hear from you.**

**Visual or written contributions (maximum 200 words) are invited and can be sent to "[matthewgibson1972@gmail.com](mailto:matthewgibson1972@gmail.com)". Images may be published online, on the website and/or in future CLL Support newsletters. Although it would be intended that as many contributions are included in the final piece, this of course cannot be guaranteed.**

**We would like to make this project a kind of 'time capsule' record of these difficult times, so get creative!**

**If you are under 60 and would like to join the Club, contact Norah:**

[Norah.grant@cclsupport.org.uk](mailto:Norah.grant@cclsupport.org.uk)



**Warning!**

We have warned previously about unscrupulous fraudsters who are targeting vulnerable people with a variety of scams.

The most recent scams we have heard of are:

- Face masks and hand sanitiser online that never arrive.
- Track and trace scams where people have been contacted to say that they have been in contact with someone with the virus. They are then encouraged to click a link which downloads a different sort of virus onto the computer.
- Emails purporting to be from a government department and offering an evaluation for tax relief because of the virus. HMRC stresses that it will never make contact by email, phone or text about a tax refund.
- Another email source people to log on to an official looking World Health Organisation site by downloading an attachment which then opens up the computer to fraud.

This, of course, is all nonsense and you should put the phone down, and refer the call to the Nation Fraud office at:

<https://www.actionfraud.police.uk/reporting-fraud-and-cyber-crime>

The consumer organisation 'Which?' have produced guidance about another scam which involves downloading a fake NHS tracking app. You can find this information here:

[https://apple.news/ApzfEG\\_mAR0esAv7oEuTRYA](https://apple.news/ApzfEG_mAR0esAv7oEuTRYA)

**The advice must be to be ultra careful, suspect anything that doesn't seem right and report it if you can. The words 'stay alert' come to mind!**

## 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@cclsupport.org.uk](mailto:coordinator@cclsupport.org.uk)

## An appeal

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.**

**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! Welcome 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 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/>

## 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@cclsupport.org.uk](mailto:coordinator@cclsupport.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.**