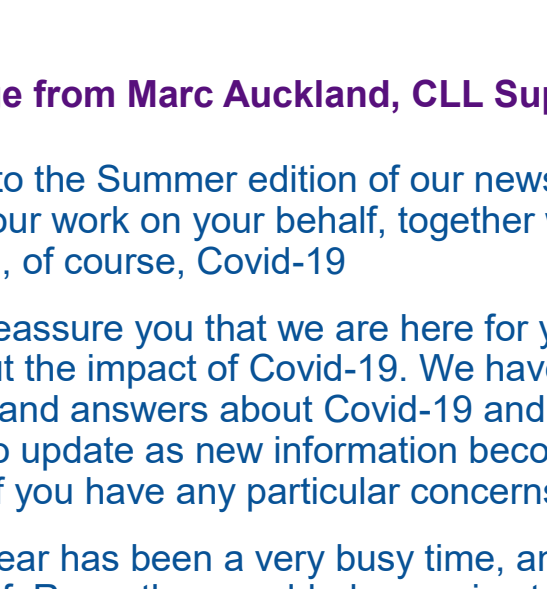


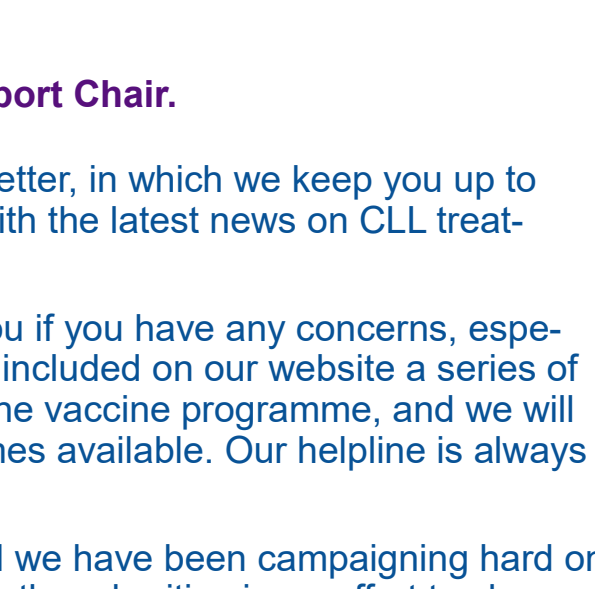
Our top stories in this newsletter



Latest Covid-19 News



First World CLL Day announced!



New treatment video

A message from Marc Auckland, CLL Support Chair.

Welcome to the Summer edition of our newsletter, in which we keep you up to date with our work on your behalf, together with the latest news on CLL treatments and, of course, Covid-19

I want to reassure you that we are here for you if you have any concerns, especially about the impact of Covid-19. We have included on our website a series of questions and answers about Covid-19 and the vaccine programme, and we will continue to update as new information becomes available.

This last year has been a very busy time, and we have been campaigning hard on your behalf. Recently, we added our voice to other charities in an effort to change Government attitudes and policies for the extremely vulnerable section of our population. Our voices are being heard, and there has been extensive coverage in the national press and television.

CLL Support is the only CLL/SLL focused charity solely working on behalf of the CLL community, and we will always put forward issues such as this to policymakers. I would encourage you to have a look at our annual report, which gives details of what we have been doing on your behalf over the last year.

In this issue we say a fond farewell to one of our long-term trustees, John Moore, who has been a highly valued colleague. We thank him for his dedication and invaluable contribution over the years and we wish him well for the future.

We are also very pleased to welcome Hilary Lindsay as our newest trustee who, I am sure, will be an asset the Board.

We still have a vacancy for two trustees, and if you feel you have something to contribute and would like to help CLL patients, please do contact me. I would love to chat and explore how you may join and help the team.

Finally, on behalf of the trustees, I want to say a huge thank you for your continued support. Thank you to everyone who has raised funds on our behalf through running, cycling or other events, and thank you for your donations and to everyone who has taken up our will writing scheme. Without your contributions we could not continue with work.

Wishing you good health.

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

Covid-19 update

The vaccination roll out has been an enormous success, but Covid is still with us, and the new 'Delta' variant, which seems more infectious, is giving concern.

Effectively, all Covid restrictions were abandoned in England from 19 July, apart from travel abroad, where individual countries have different controls and return to the UK can also mean quarantining. These rules change almost daily, and we recommend checking on the UK Government website:

Foreign travel advice - GOV.UK (www.gov.uk)

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/

Wales: Coronavirus (COVID-19) Topic | GOV.WALES

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

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

Our advice is that CLL patients should carefully consider the risks before foreign travel.

Covid-19 and CLL

Vaccination

We honestly do not know how well the vaccine works to prevent COVID-19 for CLL patients. What we do know is that CLL patients' responses to the vaccine are at best unpredictable, and when CLL patients contract COVID-19 they are at a much higher risk of poor outcomes.

There is a key role for a "circle of protection" surrounding those who are immunocompromised, consisting of other vaccinated individuals. It is important that all household members and others you are in close contact with are vaccinated.

We recommend that CLL patients, even when vaccinated, still adhere to the three tried and tested mandates for COVID-19 safety which are: maintain social distancing, handwashing, wear a well-fitted face mask.

We continue to receive lots of queries about the vaccines which are now in use. 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/

If you have a question about vaccines or Covid-19, please contact us and we will try to help: coordinator@cllsupport.org.uk

How effective is the vaccine for CLL patients?

We have received an interim report from one of the most important studies, the Birmingham University study looking at how effective the vaccines are for CLL patients. The antibody response to covid vaccinations in 299 people with chronic lymphocytic leukaemia (CLL) who had two doses of either the Pfizer or AstraZeneca vaccine was examined.

We interviewed Dr Helen Parry, who is the lead on this trial. She speaks about why the trial is important and presents the results in a very understandable way. You can watch the video here: https://www.cllsupport.org.uk/dr-helen-parry-presents-the-findings-of-research-into-vaccine-effectiveness-june-21/

You can find the full report together with our comments here: https://www.cllsupport.org.uk/birmingham-university-covid-vaccine-study-results-released/

It's important to remember that the antibody response recorded does not include T-Cell response, which is an important component of the immune system. It is likely that your T-cells will be active in mounting a defence against Covid-19. For a good discussion on the importance of T-cells, watch this short video: https://www.medpagetoday.com/opinion/marty-makary/92310

One other point about vaccinations

You may have had a Covid test which has been negative, even after having a vaccination. This does not necessarily mean that you don't have antibodies, because the standard tests only check for whether you have had Covid and won't show up the antibodies created by the vaccine. For this you would need a different and much more complicated test, which is not generally available.

Masks

It looks like we will be wearing masks for some time yet. They may even become a permanent feature of our lives from now on.

One of our trustees has prepared an analysis of some of the types available, with comments on their comfort and efficiency. You can find the details here: https://fb.gv/s1h4b

First ever world CLL day!

We are very pleased that we will be a major participant in the first World CLL Day on September 1st 2021. This will be part of Blood Cancer Awareness Month.

Share your voice!

On 1st of September the CLL community is launching World CLL Day to give those affected by a diagnosis of CLL a much needed voice, raise awareness and improve understanding of the challenges involved in living with CLL.

This is an opportunity to come together and raise awareness about the vulnerability of CLL patients and other immune compromised people during the pandemic.

Prior to World CLL Day, we are collecting brief quotes to allow patients and carers express what it's like to live with CLL in this current pandemic. These quotes will be shared on the dedicated website and Social Media as part of the campaign communications.

We would appreciate if you could share your voice and submit your quote and a picture (optional) Simply email your quotes to: coordinator@cllsupport.org.uk

This is an opportunity for us to draw attention to CLL on the world stage. Further information will be posted in our newsletters and on our website, so watch this space!

The new drugs - how they are changing CLL treatment plans

We were extremely pleased when two leading CLL consultants agreed to give an insight into the working of Multi-disciplinary Team (MDT) meetings in the light of the new treatments becoming available. We think you will find some of the conclusions very interesting and welcome.

You can find the video on our website here: https://www.cllsupport.org.uk/the-new-drugs-how-they-are-changing-cll-treatment-plans/

A patient's story by Steve Abrahams

I was diagnosed March 2017, Aged 54. Looking back, my GP was monitoring my blood for some time, perhaps hoping my white blood count would normalise, it didn't.

I was sent to my local hospital Haematology department for further blood tests, at the time not knowing why. The haematologist said that from my records, she believed that I had Chronic Lymphocytic Leukaemia. All I heard was the word LEUKAEMIA.

I was devastated, my paternal grandmother died from Acute Leukaemia, and from memory (50 years ago), she was taken to hospital and died a few weeks later. You can imagine the thoughts going through my head about getting my affairs in order.

I then did exactly the opposite to what I would now recommend to any newly diagnosed patients. I hit the internet, hard. It made matters worse. My advice now would be to look at only UK based websites, limited to of course the CLL Support, Macmillan, Leukaemia Care, Blood Cancer, NHS. The information is then up to date and refers to drugs available to us in the UK.

I wish I had known about CLL Support, along with their helpline and Facebook presence. There is also an associated WhatsApp group for the under 60's. These groups are great for information and advice.

My GP said that as my CLL was discovered at an early stage, the chances were that I would be on Watch and Wait (Worry), without ever needing treatment. This was some weeks after the diagnosis, and I did my best to forget about it. I got back into a normal routine, which included running and going to the gym. In early 2019 I was training for a half marathon. I found that I was only able to train one week in four. I kept getting colds, sore throats.

I became rather ill with what I thought was a chest infection in the autumn, coinciding with Jury Service. I recall walking from the carpark, about a half mile away from the court, up a slight incline. I couldn't believe how difficult that walk became over the 2 weeks I served.

The day after we delivered the verdict, I was admitted to hospital with a Haemoglobin level of 5 point something.

I spent 5 days in Hospital, in a side room to avoid infection. I was given high doses of steroids which didn't restore my blood levels and was given a blood transfusion. My Haematology consultant said that I would no longer qualify for the Flair Trial, as I was still on a high dose of steroids, unless I could get the dose down to 10mg by the year end, some 8 weeks later. My last dose of Prednisolone was 31 December. I am told that my underlying fitness was probably the reason I responded so well to the treatment.

That January I was put forward for the Flair Trial and I was randomised to Ibrutinib and Venetoclax. I have responded very well to these drugs, with little in the way of side effects. Two and a half years later, I was told I had reached MRD Negative. In January, 3 years after starting, I am due to stop taking these drugs, but remain on 3 monthly checks under the trial.

I am convinced that my fitness assisted me significantly to overcome the AIHA and helped with the CLL too.

On the subject of fitness, I did little in the way of sport since leaving school. When I was 40, I was unfit, and overweight. I work in a stressful profession and thought that I was a heart attack waiting to happen. I was determined not to be so unfit by 50. I joined a slimming club, and enjoyed the competitiveness of the 'weigh ins', which assisted me in losing weight quickly. After losing the first stone, I began to run/jog and never looked back. I joined a gym, and despite being old enough to be a grandparent to some of the group's members, I found myself joining their Tough Mudder Team, and ran 4 such events being 10-13-mile cross country runs with torturous obstacles dotted around the course.

I have also taken part in 4 London to Cambridge bike rides. Cambridgeshire on the edge of the Fens is not as flat as you might imagine!

Last year, I entered the CLL Support 10K sponsored run which was cancelled due to COVID. Like some of the others, I ran the 10K locally, and raised £600 in sponsorship.

It would be great if we could field a team to run together next year, the impact of us all wearing the CLL Support T-Shirts might assist in raising awareness for our cause.

I would like to finish by saying that there is definitely life after diagnosis. Steve

We'd like to thank Steve for sharing his story and for the amazing amount he has raised for CLL Support. If you have a story to share, we'd love to hear from you.

Fundraising heroes!

Steve is not the only one fundraising on our behalf, and we want to thank everyone who has helped. Please do let us know what you've been able to do, no matter how big or small. We really could not manage without you and we'd love to feature your efforts here!

A special mention this month for magnificent fund raising efforts by our members.

Marielena and her friend Laura completed a sky dive for CLL Support and raised £1070!

Nick and Alison Dutton completed the ASICS 10k run in London and raised the magnificent total of £1700.00! This was helped by a kind donation from the company Nick works for, Arco Ltd. We hope to feature Alison's CLL story in a future edition of the newsletter.

Matt Gibson ran a half marathon earlier this year and raised £940.00!

We are indebted to them and all our wonderful fundraisers.

Please don't feel that you need to raise these kinds of amounts. We are so grateful for any funds you can raise on our behalf.

Trustee News

We have announced that one of our long-standing Trustees, John Moore is leaving us. John has been a valued trustee since 2015 and has been central in creating our business planning and charity governance modules. His good-natured advice has been important in helping to guide us over the last six years. He leaves a legacy he can be proud of, and the charity is much stronger than when he joined. We thank him for all his work, wish him well and happy golfing!

Although we are sad to see the departure of one trustee, we are extremely glad to welcome Hilary Lindsay to join our team. Hilary lives in Northampton with her husband Colin. In Hilary they are both retired. They have both been involved in charity work for 25 years. Hilary had previously run several marathons to raise funds for Coast and in 2017 she and Colin completed Wainwright's 200 mile Coast to Coast walk across the north of England.

Hilary was diagnosed with CLL in 2009, following pre-op tests before kidney replacement surgery. She feels herself very fortunate that her white blood cell count is still less than forty and she has not yet needed any treatment.

Trustees are vital to keep CLL Support running and without them, we would cease to exist.

We currently have two vacancies, and if you feel you would like help and have something to contribute, we would like to hear from you.

Trustees each have specific roles and responsibilities, supported by the other trustees. We would like to recruit someone with experience in Information Technology and another who can advise on Business Planning and Governance.

In the first instance, please contact Marc Auckland: marc.auckland@cllsupport.org.uk

We look forward to hearing from you.

Under 60 Club

Membership in the Under 60 Club WhatsApp group has grown steadily. It is a very busy forum for people balancing CLL with Covid in the workplace and young families, as well as sharing concerns over Active Monitoring and starting treatment. Many thanks to everyone in the Under 60 Club for the continued success of the group.

Just a few of the comments from our members:

"I knew there'd be a voice of calm and reason from this group. Thanks for the top tips x"

"I love this group and although I miss a lot it's great to catch up with everyone's news x"

"I love this group - you're all such inspirational people! Catching up on messages and can see lots of you are dealing with starting treatment and so just wanted to say that I'm thinking of you all and sending lots of positive energy your way."

If you would like to find out more, or to join the group, please contact Norah at: 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 CLL 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.

On September 1st we will be launching an entirely new section of our website devoted to a system for helping mental health. This is called Acceptance and Commitment Therapy (ACT). This will be a major step for us in looking after mental health. We'll be giving more details nearer the day.

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, many solicitor consultations are taking place online. However, as restrictions are eased, it will be possible to see a solicitor face-to-face.

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 last year. 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.

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 £1080.36.

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 from fellow CLL sufferers. Why not have a look at: https://healthunlocked.com/cllsupport/posts/146062888/ct-scan-results?utm\_source=notification&utm\_medium=email&utm\_campaign=email\_individual\_new\_blog\_post\_title

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 let 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.