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Newsletter

April/May 2023 - Issue No 03

Our free helpline: 0800 977 4396

Welcome to our latest newsletter, and I hope you find it informative and useful.



It was always going to take at least two of us to fill Marc Auckland's shoes. He has done an amazing, indeed reMARCable, job as our chair over the last 4 years, including taking us online during the pandemic.

You will be pleased to hear that at our handover board meeting we gave Marc a book full of thank you messages from some 50 colleagues who had worked with Marc,

Very often they did indeed say he had been reMARCable!

I am very honoured to now be the Chair of CLL Support and John Greensmyth has stepped into the new role of Vice Chair.



We complement each other well. Not least as John has had every CLL treatment that has been available over the last 30 years and I have been on active monitoring for 15 years. Between us we demonstrate how different everyone's CLL experience is and also what fantastic developments there have been with new treatments in recent years.

I am sure you will appreciate that CLL Support is a patient and supporter led charity, run by volunteers, who are all keen to give something back to the CLL Community. We are still looking for some more Trustees, in particular people who have website and communication skills. Do please get in touch with John or me if you feel you might be able to help.

We are very pleased to have introduced a new feature in this newsletter. Last year over 700 of you responded to our CLL Support Survey. You told us about what matters to you and we are now responding with more support for you in our new section entitled "We asked, you said, we did." We do hope you will find this practical feedback of value.

John and I are very much looking forward to meeting those of you who can attend our Liverpool Conference on 25th May in person, and to waving to those of you who join the event online.

With our very best wishes

Hilary Lindsay

Chair, CLL Support

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John Greensmyth

Vice Chair, CLL Support

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We win a new first-time treatment for CLL patients!



On Friday 21 April, NICE announced approval for the combination of ibrutinib and venetoclax for first line treatment for all CLL patients in England and Wales.

It's difficult to over-emphasise how important this is for CLL patients, and it moves a step closer to eliminating chemotherapy completely.

Our patient advocate was the only contributor to the NICE committee to make the case for using the new combination for first-line treatment, and we are intensely proud of their hard work and determination throughout. It will bring huge benefits to thousands of patients in the future. One of our members, Steve Abrahams, also spoke to the committee about his experience being on the treatment.

The committee, unusually, made a point of mentioning the contribution:

"During scoping consultation, a consultee highlighted an urgent need for access to novel treatments for younger, fitter patients with chronic

lymphocytic leukaemia as currently only fludarabine, cyclophosphamide and rituximab (FCR) or venetoclax plus obinutuzumab via the Cancer Drugs Fund is available to them. This has been addressed by committee because ibrutinib plus venetoclax has been recommended for everyone with untreated chronic lymphocytic leukaemia."

Without this intervention, it's very likely that this vital combination would have been denied to many patients. We are very grateful to the committee for listening to the voice of the patient, and will continue to press for the acceptance of new treatments in the future. We are currently working on a submission to the Scottish Medicines Consortium (SMC) for the same combination, and we are hopeful of success there also.

** The SMC will shortly consider an application to approve the use of Ibrutinib and Venetoclax as a combination treatment. CLL Support will participate in the process and we are seeking testimony from any patients in Scotland who have had this combination either as part of a trial or as part of a treatment plan. Anyone wishing to know more about this should please contact John Greensmyth at john.greensmyth@cllsupport.org.uk.

A further submission to NICE is also underway for zanabrutinib, a 'third generation' BTK inhibitor. We will, of course, keep you informed.

Covid vaccination - an important message

The NHS has announced that the next (7th) round of Covid vaccinations started on 17th April. Vaccinations for nursing homes started on 2nd April. You should receive an invitation soon, if you haven't already had one.

Full NHS advice can be found here:

<https://www.gov.uk/government/publications/covid-19-vaccination-spring-booster-resources/a-guide-to-the-covid-19-spring-booster-2023>

Unless you had a severe reaction to previous Covid vaccinations, we strongly recommend you should receive this one. Although Covid infections are very much reduced from last year, it's still around in the community.



Do you have CLL and are you taking acalabrutinib or ibrutinib (BTKi therapy)? The IMPROVE study is investigating whether pausing BTKi for 3 weeks' can improve immunity for the Spring 2023 COVID-19 vaccination.

Chronic Lymphocytic Leukaemia (CLL) patients taking either **ibrutinib or acalabrutinib** (BTKi therapy) are invited to join the IMPROVE study. The study is running in 11 hospitals across England and Wales and will

investigate if pausing ibrutinib or acalabrutinib treatment for 3 weeks around the time of vaccination can improve immunity to COVID-19 for patients. The government has recommended patients to have a COVID-19 vaccine this Spring from **17th April**. If you are taking ibrutinib or acalabrutinib and are interested in taking part in IMPROVE, please can you contact improve@ndorms.ox.ac.uk or call the trial unit on **0808 175 1455**. A list of hospital sites running the study is available at <https://improve.octru.ox.ac.uk/>

Covid-19 infection data ending

The Office for National Statistics (ONS) has stated that it will no longer be issuing Covid infection data, which is the information we provide in our newsletters and on the website. Similarly, the NHS has stopped its 'proximity app' for mobile phones which indicated if you had been near an infected person. This is good news, as it means that Covid infections are now very low, or very mild. We appreciate that many CLL patients are still cautious about mixing with other people, but the threat level has diminished substantially. However, it's still important to make sure your Covid vaccinations are up to date - see above.

Reserve your place for our Liverpool conference!

Thursday 25 May 2023

After the sell-out Cambridge conference we are pleased to announce that our next conference will be in **Liverpool**.

Our keynote speaker is Prof. Andrew Pettitt, and the title will be:

"Owning your CLL Journey"



Andrew Pettitt is a Professor of haematology at the University of Liverpool and Consultant Haemato-oncologist at the Clatterbridge Cancer Centre NHS Foundation. He is a regular and very popular speaker at our conferences.

Also speaking at the conference will be:

Dr Stella Williams

and

Lead Haematology Research Nurse, Jane Tinsley

The full programme will be as follows:

09:00 Registration Desk Opens

10:00 Conference Starts. CLL Support Intro and Housekeeping

10:15 **Introduction to CLL - Dr. Stella Williams**

11:00 Coffee Break

11:15 Patient Speaker: Moira Griffiths-Parr in discussion with RN Jane Tinsley

12:00 Round Table Discussion - ALL

12:30 Free Lunch

13:30 Data Analysis: How does that help my CLL?

14:15 Owing your CLL Journey: Pulling the Threads together including a panel Q&A led by Prof. Andrew Pettitt

15:50 Summary

16:00 Close

Demand for places will be high, so please register as soon as possible.

We look forward to welcoming you!

[Please register for this conference here](#)

If you missed our Cambridge conference, you can find the videos here:

[Click here for Cambridge conference videos](#)

We asked, you said, we did

In your responses to the CLL Support Survey you told us that fatigue was by far the most common side effect you were suffering from. Over half of the 700 of you who replied mentioned it. We have been trying to find out what support we might be able to give you.

We found that there are four recognised elements to Fatigue:

- **physical fatigue** (e.g. your level of physical energy)
- **cognitive fatigue** (e.g. your concentration and clarity of thought)
- **living with fatigue** (e.g. your ability to carry out activities of daily living and social activities)
- **emotional fatigue** (e.g. feelings of distress or upset)

[Read more about our findings here](#)

New information on the STATIC trial released

We are delighted to be able to announce that the STATIC trial has now started! STATIC is now open at several hospitals and the first patients have joined the study.

This will be of interest to anyone who was on the FLAIR trial, and anyone who is taking Ibrutinib as a second or later line of treatment.

You can find the full details on our website here:

[STATIC trial announced. Find details here](#)

Vaccination is important for CLL/SLL patients

Vaccination guide and log for people with CLL/SLL

This information has been provided by consultants from the UK CLL Forum and their partner charity, CLL Support.

Introduction

If you have CLL or SLL, you are more likely to suffer infections. This is because CLL can weaken your immune system, even at an early stage in the disease. It is important, therefore, to make sure you are fully vaccinated for a range of infections as soon after diagnosis as possible. Your medical team will advise you about this.

Caution

You must not receive vaccines which contain live or attenuated (weakened) viruses.

These include: yellow fever, oral polio, measles, mumps and rubella (MMR), and the live shingles vaccine (Zostavax).

The non-live shingles vaccine (Shingrix) is available in the UK for those aged 70-79 and is safe for CLL patients.

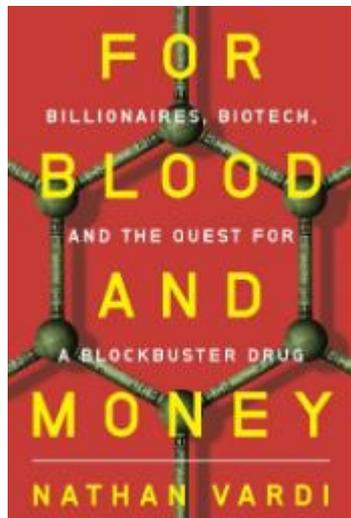
CLL patients should avoid children for at least a week who have recently received the nasal flu vaccine and the nasal polio vaccine, as they can pass on the live virus.

Vaccinations

The correct vaccinations are very important for CLL patients. We've updated our guidance on vaccinations, and you can download our leaflet from our website here:

<https://www.cllsupport.org.uk/information-on-support/further-information-resources/order-publications/>

Something a little different (1)!



Earlier this year, the book **For Blood and Money: Billionaires, Biotech, and the Quest for a Blockbuster Drug** was published, telling the incredible story of how the first BTK inhibitors that revolutionised the treatment of chronic lymphocytic leukaemia/small lymphocytic lymphoma came to be. Author Nathan Vardi conducted a wealth of research to uncover the history behind the pharmaceutical companies and the physician/scientists that developed the drugs, the enormous amount of

funding from venture capitalists and the brave patients that entered these trials who together made it all possible. It's an incredibly absorbing read and shows just how close ibrutinib came to never being produced at all.

Health matters



Are you taking a BTKi treatment, for example ibrutinib and acalabrutinib? Then you should avoid certain foods, including:

- grapefruit or products from grapefruit,
- Seville oranges or products from Seville oranges,
- star fruit or products from star fruit.
- Some lists also include pomegranate.

These fruits inhibit an enzyme called CYP3A, which is essential for BTKi drugs to work correctly. So, best to avoid them.

Can you really boost your immune system?



This is an interesting extract from the views of two doctors in the USA:

"The idea that we can boost our immune system is everywhere, and it seemed to multiply exponentially during the pandemic. Possibly you or someone you know tried to stock up on things like zinc, vitamin D, or Vitamin C when the pandemic started.

Maybe you even looked for other products that say they'll boost your immune system. There are tons of them out there -- "wellness" shots and herbal supplements and teas and such like.

One of the reasons why this is so pervasive is most of us haven't been taught how our immune systems really work. And the truth is... you can't boost your immune system... The Immune Boosting myth preys on our fear of getting sick and completely misrepresents how the immune system works...and how incredibly complex it is..."

The conversation between **Dr. Jen Gunter** and **Dr. Katherine Gundling**, an immunologist, can be found here:

[Can you boost your immune system? \(Transcript\) | Podcasts | TED](#)

For blood cancer patients, there may be times when certain vitamin and mineral levels may be low, and supplements are needed to help. This is something your consultant will advise on, and they they should be told about any you may be taking. Please remember that excess doses of supplements can be toxic.

A new CLL trial

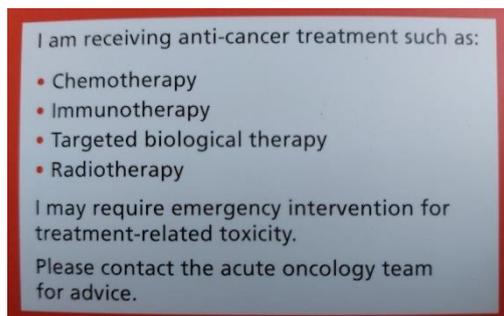


It's very encouraging that so much research is going on to find new treatments for CLL/SLL, and to improve on existing treatments.

A Phase-1 trial for a new CLL treatment (BGB-11417) is recruiting at the Oxford Cancer and Haematology Centre.

This is an BCL-2 inhibitor, similar to venetoclax. Please note that this trial is at an early stage, designed to establish dosage, and is designed for relapsed/refractory patients only, not first time treatment. Your consultant will have details. More information here:

<https://clinicaltrials.gov/ct2/show/NCT04277637>



Do you have a card like this?

When you are approaching treatment, you should be given a card similar to this. It's very useful if you need to attend hospital in an emergency, perhaps at a hospital other than your own.

You, or someone with you, can hand the card to the doctor attending you to inform them of your condition.

It also shows the emergency number to contact your medical team.

If you are in or approaching treatment, and you don't have one of these cards, we suggest you ask your medical team to issue you with one.

Something a little different! (2)



These 3 little beach huts at Lusty Glaze Beach need a new home!

The 3 new owners will have the once in a lifetime opportunity to own a little piece of a Cornish beach. The huts will need a few repairs and some TLC but in the right hands they will be unique. How cool to have one of them in your back garden!

One of the owners was diagnosed with CLL in July 2019. Tracey has been on watch and wait, living a fun-filled active life up until now. Next month she will start treatment – venetoclax and obinutuzumab. She is looking forward to be being a regular human being for a while.

It's because of their links to CLL that the current owners have very kindly decided to accept donation offers for the beach huts and the proceeds will be given to CLL Support. How wonderful!

A big, big thank you from all of us at CLL Support.

For a chance to own a hut, you can email events@lustyglaze.co.uk

Or take a look at their facebook page:

<https://www.facebook.com/120415094637010/posts/pfbid0382bq98AEdfReA538mpy2syMMW3pCLNoBEHchjnmyhDpu75TuhirnjGEs8oRV7Ksnl/?app=fbl>

More fundraising

The contribution to our fundraising from our members is amazing. Here are just a few examples of their efforts. We are extremely grateful to everyone, and without you, we would not be able to carry on our work. You are all stars! Thank you!



Samantha Daley completed the Sheffield Half Marathon on Sunday 26th March in memory of her beloved Dad who passed away after being diagnosed with CLL. She wanted to raise awareness and also ensure research for the illness to help others moving forwards.

Samantha has raised an amazing £350 from this event for CLL Support Association at the time of going to press.

I'm sure everyone would like to join me in say a big well done to Samantha and thank you so much for doing this. It really is appreciated by us all at CLL Support.

If Samantha has inspired you to take part in a fundraising event yourself, please contact me for a fundraising pack:

cherry.mills@cllsupport.org.uk



For all those runners among you, the ASICS London 10K takes place on Sunday 9th July this year.

It is the most iconic capital city 10K race with live bands, DJs and cheering fans to motivate you all along the River Thames, Westminster Bridge and by Big Ben. Sounds amazing and what a great sense of personal achievement when you reach the finish line.

Tickets are being advertised now at £45 (plus £3.15 entry fee) each and are available by clicking on the link: [ASICS London 10K | Limelight Sports Club](#)

If you would like to enter this iconic race and raise money for CLL Support, it may be possible to refund all or part of the entry fee by

signing up to our 'Pledge' scheme.

To obtain a fundraising pack and a pledge/refund application form, please email cherry.mills@cllsupport.org.uk.

Refund for Event Fees

Are you thinking about taking part in an organised fundraising event? We may be able to refund all or part of your entrance fee up to a maximum of £50 depending on demand. All you need to do is agree to fundraise a minimum amount for CLL Support. For more information or for a pledge form and fundraising pack, please email: cherry.mills@cllsupport.org.uk

Now that Smile.Amazon has come to an end, a part of our income has been lost. You may be looking for an alternative to sign up to.

Below are a couple of options. Sign up for free and raise money when you shop online. It could be your weekly food shop, a holiday, annual insurance, household appliance, etc. **At no additional cost to you**, it's really easy to raise money for us. It just takes a few minutes of your time to sign up.



easyfundraising - <https://www.easyfundraising.org.uk/>

easyfundraising partners with over 7,000 brands who pay it a commission when people start their shop via its site or app. It then turns this into a donation for your chosen cause. You can see how much you've raised for CLL Support, and get updates on when we get paid.



Charitable shopping - <https://www.charitable.shopping/>

When you buy through Charitable Shopping, its partner shops and service providers pay it a 'thank you' fee, which it transfers over to the charity. The donations are sent through JustGiving to the charity directly. Supporters can register, select their charity, and start donating straight away.

Why not give it a try - it's easy

If you have fundraised for us do please let us know so that we can thank you and perhaps feature you here.



One of our key missions is to make our resources accessible to everyone with CLL, and to their families and friends.

To this end, we've been looking at ways of opening up our website to people with disabilities, for example those who are partially sighted. In addition, we want to be welcoming people whose first language is not English.

We're pleased to announce that we've now installed an accessibility tool on our website, which you can find in the top right hand corner. It has numerous tools to help, and is very easy to use. Try it out!

Can you help, please?



Please can you share your CLL story?

For those who attend our conferences, an undoubted highlight is one of our members sharing their CLL story. People find it enormously encouraging to hear how others coped with their CLL, and to know they aren't alone.

We need people to step forward and tell their CLL stories so that we can feature them at our conferences and in our webinars. If you can't attend in person, we can video you at home.

Everyone's story is relevant. Do you perhaps have a hobby or job that would help to show how you have managed with CLL? You can do this with a partner, or indeed your partner can tell their tale. Have a look at how other members have told their story:

[Sue and Elizabeth's story](#)

If you are happy to share your story for a few minutes, we'd love to hear from you. You would be helping other people with CLL.

Please email: Lewis.Troke@cclsupport.org.uk.

Many thanks

Marc Auckland

HealthUnlocked

HealthUnlocked is our very active on-line forum, where you will find support and knowledgeable, reliable advice on

all things to do with CLL. The site also has a very comprehensive resource of CLL information, which is updated regularly, and is moderated by our team of Administrators and Volunteers. You can check it out here:

[HealthUnlocked](#)

**Do you have a will? If not, we can help
Or perhaps you need to change your will? We can help, too.**



Our new free Will-writing service.

We do understand that the decision to write a will can be a delicate topic and must be handled sensitively. But it is essential for most people to have a will in order to safeguard their interests after death.

It would be wonderful if you could read on before deciding if this is something you wish to 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 (or online if you prefer) 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 discrete and 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](#):



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 always try to.

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.

You can contact us at membership@cllsupport.org.uk

We look forward to hearing from you!