

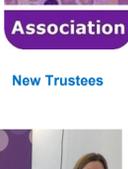
# CLLSA NEWSLETTER

A regular newsletter brought to you by the Chronic Lymphocytic Support Association

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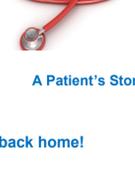
## Our top stories in this newsletter



New Trustees



Bournemouth Conference



A Patient's Story



### Bournemouth Conference. Going back home!

*"The opportunity to meet others with CLL was extremely valuable."*

*"...one of the best conferences overall."*

For our third conference of the year we were very pleased to go back to our roots! CLLSA began in Bournemouth in 2004.

For the first time we held the conference on a Saturday and this proved to be a resounding success, with a record number of attendees and no less than four expert speakers. In addition, three patients and a care partner told their very moving stories.

In the morning Dr Ram Jayaprakash, consultant haematologist, gave an introduction to CLL, what it is, how it develops and illustrated how complex it is. He also spoke about the FLAIR trial. This was followed by a talk about the biology of CLL from PhD student Lara Makewita.

The keynote talks in the afternoon were given by Dr Helen McCarthy on how CLL affects the immune system, and Dr Renata Walewska on CLL treatment old, new and in the future.

The new CLLSA Under 60s' Club was launched at the conference in recognition that, although the average age of diagnosis is about 70, there is a significant number of patients below that age, many of them much younger. See elsewhere in the newsletter for more details.

We would like to thank the Royal Bournemouth Hospital's CLL team, the CLL Support coordinator, organising trustees and contributing members for all their hard work in making the conference such a success.

The videos from the conference are on our website here:

<https://www.cllsupport.org.uk/article/bournemouth-members-meeting-may-2019>

### Our other Conferences this year. Make a note!

**Newcastle**—19 July

**Nottingham**—5 September (Registration now open)

**London**—21 November

**Places go very quickly, so book yours now!**



### A Patient's Story

#### Norah Grant

I have been on Watch and Worry since the end of 2015. And I worry!!!

When it will get worse? When will I need the chemo? Will this cough turn into pneumonia, and then sepsis? And what about my moles? Will they turn into melanoma? Can my spleen get any larger??

My CLL inflates like an air mattress cushion under my life. But it's not a soft cushion of air, its full of Stress and Anxiety and Fear and Worry. Ordinary things like working and riding the Jubilee line that screeches around corners and downhill, become inflated with that extra layer of stress. And one day that screeching popped my CLL air mattress and I just started crying. While standing up in the Underground. Feeling a fool.

Living with CLL is stressful and I think the shock of the diagnosis has a lasting effect on our psyche. I was given the news over the phone when I was home alone that I had leukaemia or lymphoma in November 2015. Then a while later, in the middle of all the tests, I was again told over the phone when I was home alone, that it was probably the bad kind – a rather deadly lymphoma. I'm not sure how that news can be softened. I appreciated being kept up to date, and I like my doctors in Canada, but getting that news is traumatic. After Christmas when the CLL diagnosis finally came there was relief. But I don't like it called "the good kind" of cancer.

Back to that first phone call in the kitchen. Luckily, I had a previously arranged lunch date with a friend two days later. I called my friend on the day of the lunch to say I was not going and managed to tell her why. She was at my house in 10 minutes. She is a breast cancer survivor and so she got it! She understood what I was going through. But if I hadn't had that lunch date already set up, I never would have called her. I would not have reached out to anyone beyond my loving, but also shocked, husband.

My friend sat me down at the kitchen table and said call your doctor back and get more information. I thought she was a genius! So simple! And so important! But beyond my capability at that time. I am so lucky she was there on that day, She was a rock to me during that time. We need emotional support from people who know cancer on the CLL journey.

A sense of humour is also important. My theme song is "Everything Gives You Cancer", by Joe Jackson. When people tell me something is bad for me, I sometimes say, it doesn't matter! I already have cancer!

Connecting with other people who have CLL at the Conferences, on HealthUnlocked and the Under 60s Club helps me keep positive. I am thankful for all the good doctors and treatments we have, and for the good health I have right now.



### Under 60s' Club

CLL tends to be an older person's disease, and as a result, younger patients and their partners can feel isolated. We feel this is unfair and decided to try to do something about it, so we launched the Under 60's Club at the Bournemouth conference. Our trustee on their table writes:

*"There were ten rowdy youngsters around the table at the back of the room to launch the Under 60s Club in Bournemouth. Seven with CLL and three partners. One has had FCR, two are on Ibrutinib, four on "Watch and Wait". The Bournemouth Conference was the first time most of them had met someone with CLL and they launched without hesitation to talk about travel insurance, low potassium, fatigue, worry, work and stress, whether CLL is a disability, and would that make them eligible for benefits? Also, can they all get the NHS exemption card? Most are working full time and that is the main reason they are different from the over 60 crowd; retirement is not always an option for relieving stress. Hearing about each other's experiences at Dimbleby Cancer Care, MacMillan and Maggie's were welcomed. Their concerns and questions were answered at the Conference, or soon after, and they were very pleased with the day. The Under 60s' Club continue to support each other in their WhatsApp and email groups."*

The group continues to grow from strength to strength, and if you would like to join, please contact Norah at: [norah.grant@cclsupport.org.uk](mailto:norah.grant@cclsupport.org.uk)



### CLLSA Champions

We now have over a hundred Champions around the country. Champions are members who have volunteered, for example, to put leaflets into clinics whenever they attend for an appointment. This is extremely valuable in increasing our membership and helping more patients. Being a Champion doesn't take much time and can usually be fitted in normal clinic appointments. We are always looking for more Champions. If you would like to help or for more information please contact:

[marc.auckland@cclsupport.org.uk](mailto:marc.auckland@cclsupport.org.uk)

### What we are doing on behalf of our members

We thought you would like to hear about some of the things we are engaged in on behalf of members.

#### Campaigning

In the last year, we helped to mount a major campaign to reverse an NHS decision. This would have restricted a new drug, Ibrutinib, being available for relapsed patients. The decision was reversed eventually, and we will continue to press the case for patients to receive the best available treatment.

#### N.I.C.E. (National Institute for Health and Care Excellence).

This is the body which provides national guidance on the use of new treatments, and we have made three presentations to them over the last year. The first was successful, and as a result, a new combination of drugs is now available. NICE is considering the other submissions and we will keep you informed.

#### Representation

Our Trustees represent us on several important bodies, including Cancer 52: The All-Party Parliamentary Group on Blood Cancer (APPG); The UK CLL Forum; the Blood Cancer Alliance, as well as advising pharmaceutical companies on becoming more patient-centric.

#### Conferences

This year we will hold six conferences around the country where patients and their care partners can meet others with CLL and learn more about the disease from the leading experts in the country. These conferences are a significant part of our work and are rated very highly by attendees. We will alert you when registration opens.

### Local Support Groups

For some time, we have been keen to see how we can help CLL patients on a regional basis. Having CLL can sometimes be isolating, and from the feedback from our conferences, we know that patients value meeting other people living with CLL and their families. So, we are looking to set up local support groups where there is a demand. Our sister charity Leukaemia Care have established Groups in Cambridge, Leicester, Nottingham and Southampton. Our first group, now being set up, is on the Isle of Wight, and we would like to get others around the country.

If you would like to start a group in your area, we can assist you, including a 'how to do' guide to get you started. Please contact Sarah for more information at: [coordinator@cclsupport.org.uk](mailto:coordinator@cclsupport.org.uk)

If you would like to join the Leukaemia Care scheme, contact Kay Drew at: [kay.drew@leukaemiacare.org.uk](mailto:kay.drew@leukaemiacare.org.uk)



### Fundraising

**Tina Everett and her daughter Hazel** will be running the **Virgin/Asics 10k** in London on 21<sup>st</sup> July this year. Tina was diagnosed with CLL in 2009 and began treatment in 2013. Tina's Just Giving page is here:

<https://www.justgiving.com/fundraising/tinaeverett>

and funds raised go straight to CLLSA, so please help all you can.

**Some of our other runners are:**

#### Jenny Cann

<https://www.justgiving.com/fundraising/jenny-cann2>

#### Team Wilkinson - Molly, Tom, Jack and Max

<https://www.justgiving.com/fundraising/molly-wilkinson>

#### Giuseppe Boscherini

<https://www.justgiving.com/fundraising/gboscherini>

#### Molly and Laurie Wilkinson

**We wish them all good luck and thank them for all their efforts!**

**Emma Collins** will be trekking the **Great Wall of China** to raise funds for CLLSA this August. She will be staying at hostels along the way, where she hopes to be able to get a few hours' sleep! Emma is grateful for the help CLLSA have been able to give to her mum and Emma's' Just Giving page is here:

<https://www.justgiving.com/fundraising/emma-collins77>

**We are enormously grateful for all our dedicated fundraisers without whose efforts we would not be able to carry out all the work we do.**

We know that many more of our members are fundraising for us in all sorts of ways, and if you, or someone you know, is doing a challenge of any kind, do please let us know, and we will publicise it here.

#### If that doesn't appeal.....

A relatively painless way of helping CLLSA if you don't fancy so much strenuous activity, 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, but CLLSA 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 CLLSA will pop up.

We only receive a small amount (£0.01 per £ spent), but it soon adds up so please do use it!

## HealthUnlocked

### 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 almost 13,000 members, and the site is moderated by CLLSA volunteers to ensure the information is up to date and accurate. 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/>

### Trustee News: New Joiners and Fond Farewells to one of our Founders

We welcome two new trustees this month:



#### Norah Grant

Norah was diagnosed with CLL in December 2015 and has been on Watch and Wait, which she admits has involved a lot of worries as well! She prefers the new term, Active Monitoring. Norah will bring her experience as a primary teacher to help keep the "kids" inline in the Under 60s Club. Norah is looking forward to bringing with conferences, the Helpline, and to doing what she can to help more awareness of the emotional impact of a CLL diagnosis to clinical professionals. Norah enjoys rambling and skiing and is a guide of Southwark Cathedral. In September 2016, Norah moved to London from Canada with her husband.



#### Lewis Troke

Lewis was diagnosed with CLL in November 2017. He spent 40 years in the IT Industry, the last six in Singapore, before retiring, and returning to live in the Winchester area. Like many people with CLL, Lewis had little idea that he was seriously ill. He presented to his GP with a sore throat. Following a blood test, he was admitted to Winchester Hospital for further assessment. Since being diagnosed, Lewis started treatment (Rituximab) in February 2018, and Ibrutinib in May 2018. Since that time, he has had a steady and progressive improvement in his bloods and general health.

Having received amazing treatment from the NHS, Lewis joins the CLLSA Board of Trustees to support fellow travellers and put something back into the system.

### Founder Trustee Leaves Us

#### Chonette Taylor

We pay tribute to Chonette Taylor, one of our Founder Trustees, who has decided to step down after many years' service. Chonette helped to set up CLLSA after finding very limited support for CLL patients following her diagnosis. From those early beginnings with just a few members, she worked to build us to our current membership of over 3,000. She was key in organising conferences and has been a constant presence at our events, including the London 10k run!

We are enormously grateful to Chonette for her contribution over the years and wish her well. She will be writing about the history of CLLSA for an article on our website. Look out for it!

#### 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 CLLSA's profile, allowing other people living with CLL to discover us. CLLSA is the only UK charity dedicated to providing education, support, and advocacy to help empower people living with CLL.**