

CLLSA NEWSLETTER

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

SEPTEMBER/OCTOBER 2019

ISSUE 05

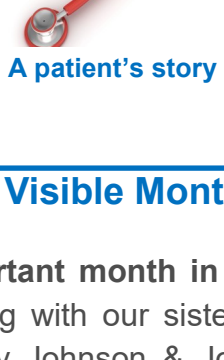
Our top stories in this newsletter



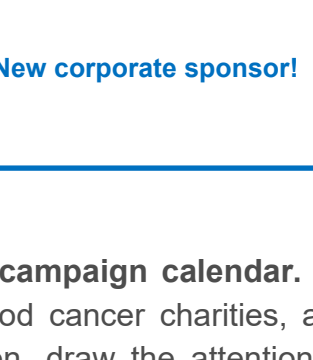
Blood Cancer Awareness



Newcastle conference



A patient's story



New corporate sponsor!

Month



Make Blood Cancer Visible Month

September is an important month in our campaign calendar. It's the time when we, along with our sister blood cancer charities, and pharmaceutical company Johnson & Johnson, draw the attention of politicians and the public to the condition.

DIY SOS star and celebrity designer, **Laurence Llewelyn-Bowen**, will be the official ambassador of the 2019 awareness campaign. Make Blood Cancer Visible is a nation-wide campaign which aims to improve earlier recognition and diagnosis of blood cancer by increasing awareness of the signs and symptoms - because early detection of cancer saves lives.

Blood cancer is the 5th most common cancer and the 3rd biggest cancer killer in the UK. Yet there is still low awareness of blood cancer and its symptoms. Our aim, and the reason we are taking part in this campaign, is to correct this.

Laurence, who lost his father to leukaemia when he was just nine years old said: "The impact of my father's death was huge, and it was all so quick. He was ill at Christmas and he was dead by July. When people were brave enough to ask what my father died of, and I would say leukaemia, people didn't know what that was."

Look out for more activity in the press and television during the month of September.

Newcastle Conference

This was our fourth conference of the year and the keynote speaker was Dr Scott Marshall, Consultant Haematologist and clinical lead for CLL in the North East. His talk on "What should I know now that I have got it, what treatments are on offer and what might the future hold?" captivated the audience and sparked numerous questions, particularly about treatment options.

We also had moving personal stories from two members, Bethan Cawley and Alice Scanlon and a presentation by CLLSA Chair Marc Auckland on research aimed at understanding the experience of CLL patients and their care partners.

Our final conference this year will be in London on 21 November. Places were released this week and very quickly filled up so please email coordinator@cllsupport.org.uk if you would be added to the waiting list.

A Patient's Story

Beth Cawley

At the age of 49, life was exciting. Two of our boys were getting married and the third had a placement year at university.

In May 2015, I had a terrible sore throat but was unconcerned as I have a tendency for this; as a primary school teacher I use my voice a lot! It got worse and I went to my GP. She took some bloods and asked to see me ten days later after a course of antibiotics.

To my surprise, she then referred me to haematology. Back home that night a letter was waiting. My appointment was the next Friday.

A gorgeous, young doctor examined me for enlarged lymph nodes under my arm pits and in the groin. I had not felt anything, but he could. Then came blood tests. I was called to the consultant. A sea of faces met me. It dawned on me that there could be something wrong...

In a daze, I drove back to school. I was so shocked I told everyone. It was like drowning in a sea of untapped emotions.

I had tests over three weeks. Then the phone call came for an ENT appointment the next day and to take someone with me. I felt sick but kept myself jovial and positive. The consultant welcomed me; he told me I had a blood cancer which would need chemotherapy. I would be ill for my second son's wedding, but it was curable. I was shocked, in denial. I couldn't speak and didn't want to talk.

More shock came the next day at haematology. I had been given incorrect information; my condition was CLL. It was incurable though treatable. Treatment wouldn't commence till warranted. It was a relief that I would be well at Josh's wedding but now I had an incurable leukaemia. This still confuses and upsets me.

Watch and wait began. Suddenly my future took on a different perspective. It's like a dark hole... it's uncertain... it's isolating... No one knows how onerous it is unless they've gone through it.

Ten months after diagnosis, my blood picture had changed dramatically, and CT scans showed enlarged lymph nodes everywhere including my lungs. I needed treatment. I wanted to start as soon as possible and this was arranged.

My FCR treatment meant something active was being done. Life became confining, but already after the first round my lymph nodes had gone down substantially. It felt like a real fight but in a positive way. Six rounds, and after five months FCR was over... phew!

After the chemo I was monitored every 3 months. I found it stressful going to the haematology unit. But it has been great to feel normal for a whole half a year. Watch and wait has a different perception now. I understand my bloods. I ask questions if I don't understand.

I have been fortunate to not get any infections, but I was meticulous in every way, wiping tables if out, taking my own coffee cup to coffee shops, not touching handrails etc.

Today I'm in remission. I, mostly, feel pretty normal although my immune system is battered. I am back at work, grateful for the treatment and to have survived chemotherapy.

My advice to those diagnosed with CLL recently is allow yourself time to understand the disease, but don't let it overwhelm you. Grieve for the life you have known but know that there is life ahead with CLL.

HealthUnlocked was a place for me to offload, to get support and information and so not feel isolated. The support of others and a sense of humour help. Online buddies, through charities such as CLL Support, understand as no one else does. It really does help.

I want to live ... to live well .. to watch my kids strive for their own dreams.

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

The CLL Under 60 Club started around a table in May 2019 at the Bournemouth Conference. We formed a WhatsApp group of seven. Then we grew to 14. Now, after the last CLL Support e-newsletter, we are 35! And it still feels like we are sitting around that table in Bournemouth. We share news of doctor's appointments, holidays and travel insurance, family milestones, CLL symptoms and conferences. We don't all chat every day, but we are here for each other and we are here for you if you would like to join us.

Contact: norah.grant@cllsupport.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:

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 email Sarah at: coordinator@cllsupport.org.uk for more information.

If you would like to join the Leukaemia Care scheme, contact Kay Drew at kay.drew@leukaemiacare.org.uk

Fundraising

We are enormously grateful to all our fundraisers who give up so much of their time to help us. Without your dedication we would be unable to carry out many of the things we do to support CLL patients and their families. **So, a big 'thankyou' to just some of the people who have raised funds for CLLSA recently:**

Jessica and Elliott Lovett ran the Race for Life. Elliott's Dad has CLL. He is doing well, the cancer was diagnosed early and is now being managed. With the support of CLLSA and family around him he feels empowered by his condition.

Matt Gardom cycled the 100 mile Prudential Challenge for CLLSA and in memory of his mother. He hopes to do the 200 mile across England challenge next year.

Avril and Rob Biggins ran the Virgin/ASICS 10k run in London

Giuseppe and Riccardo Boscherini also ran the Virgin/ASICS 10k in London, completing it in just over an hour.

We thank them for all their efforts!

Emma Collins has been trekking the **Great Wall of China** to raise funds for CLLSA this August. She has stayed at hostels along the way and was pleased to receive her medal at the end of the trek! Emma is grateful for the help CLLSA have been able to give to her mum and she is still raising funds. 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.....Don't forget to smile!

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!

We are very pleased to announce that Crondall Energy have selected CLLSA to be their sponsored partner for the year. They will be entering a team for the Clarendon marathon on 6th October. Their Just Giving page is here :

We look forward to working with Crondall Energy throughout this year and wish all their marathon runners good luck.

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:

We welcome a new trustee this month:

We are pleased to introduce Michael O'Neill, our latest recruit to the CLLSA

Michael writes: I was diagnosed with CLL in 2017. Currently being periodically monitored (W&W) at James Cook University Hospital - Middlesbrough.

Interests - keeping up my strength and spirit by walking and cycling the hills and moors of the North Yorkshire National Park.

Maintaining a daily fitness regime and eating a reasonably healthy diet. I read a lot both for pleasure and academic interest.

All our trustees are volunteers and either have CLL themselves or are related to someone with CLL.

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.

Registered Charity: 1178482