

WHAT WE HAVE FOR YOU IN THIS ISSUE

We run you through the efforts for the upcoming **World Leukemia Day**, touch base and feedback on the EHA conference in Vienna, whilst chatting with acute leukemia patient, Lisa, who is currently awaiting a stem cell transplant.

World Leukemia Day



World Leukemia Day (#WLD) on 4th of September is just around the corner. Not only is this a poignant day for advocacy and awareness, it also marks a period in the calendar for many affected by leukemia across the world, to reflect on the impacts. Leukemia is the third highest cancer killer in the world.

Roughly, 437,000 people are diagnosed with leukemia annually across the world. Yet, still some consider it to be a 'good' or 'easily treatable' cancer. Though treatment in some cases can seem easier, leukemia remains a deadly disease and often misrepresented member of the cancer world.

This is why days like WLD are vital for us and many others to remind the world of the impacts of leukemia on so many across the world.

Whether a patient, carer or healthcare professional it is vital that we all collectively and collaboratively combine our efforts to raise the often distant voice of awareness for leukemia.

You may have noticed we have sent out a toolkit to support you and others in their efforts to continue to raise awareness on signs and symptoms of leukemia and the importance of an early diagnosis. If you have not already, have a look at the best ways to get involved this year for WLD.

Key messages:

- By raising awareness of leukemia and educating the world on the signs and symptoms of this condition, we can work together to help leukemia patients get diagnosed and provide better outcomes for them. You can make a difference no matter who you are and where you live.
- Encourage people to get seen by a healthcare professional. This will help reduce the numbers of preventable leukemia deaths across the world and provide patients with greater outcomes.

Calendar dates are often overlooked in some peoples minds, but these are vital, especially with a growing reliance on social platforms and technology. It gives a platform for many to discover new information and/or organisations via relevant hashtags for these days.

Join us on 4th of September for World Leukemia Day!

More information: www.worldleukemiaday.org
[#BeLeukemiaAware](#)
[#WorldLeukemiaDay](#) [#WLD22](#) [#Leukemia](#)

MEET LISA



Lisa is a mum, wife and daughter from the UK. Originally born in Germany, her life has seen her travel to a few places across the world. Sadly, in 2021 Lisa was diagnosed with Acute Myeloid Leukemia. After much treatment and a period of being out of hospital she sadly relapsed in March 2022. Lisa now requires a stem cell transplant. As she awaits this transplant, Lisa took some time to chat to us about the importance of raising awareness, and what it is like to live with acute leukemia.

What did you know about leukemia before your diagnosis?

Before I was diagnosed with Acute Myeloid Leukemia (AML), I actually I knew very little about it. I always thought leukemia was a cancer that mostly affected children, so I was really surprised to learn that the average age of diagnosis is 68. Before starting treatment I had no idea there were different types of leukemia and I certainly didn't realise the difference in treatment from other cancers. I knew that leukemia was systemic and didn't present as a tumourous growth but I did not realise that the treatment involved such high doses of chemotherapy and being an inpatient for extended periods of time.

In fact, I knew so little about leukemia and its symptoms that I ignored mine for nearly three months and was so unwell by the time I went to hospital that I would have only few days left to live.

Did you ever struggle to understand what the doctors were talking about?

When I was diagnosed I was in pretty bad shape and struggled to take in a lot of the things I was being told. I was already dazed and confused due to being so severely anaemic, so once I was diagnosed I spent much time sleeping. Although it was hard to hear that I was seriously ill, at least I finally knew what was wrong with me. The consultant who gave me my diagnosis was incredibly kind, calm and gentle. She gave me morsels of information at a time, rather than overloading me with everything at once. I can't say I completely understood the things I was being told through my confused state but I also had a specialist haematology nurse on hand who made sure she came by a lot in the first few days to help answer any questions I had.

Do you feel like leukemia is spoken about enough?

I don't feel leukemia is spoken about enough. It's one of the lesser known and lesser understood cancers in my opinion. People actually often refer to it as 'a good cancer'. I can wholeheartedly tell you, there is no such thing. When I had my first Hickman line fitted, I had only been diagnosed three days previous and was still feeling incredibly frightened. I explained my diagnosis and concerns to my surgeon but he actually scoffed and said that it was a very treatable cancer so I needn't worry. In reality it only has a 40% chance of cure and this can often only be achieved by high risk, potentially life-threatening interventions such as stem cell transplants. I feel like even throughout the medical profession there is a huge gap in knowledge about leukemia, not only in the average person.

What do you think is the most powerful way of raising awareness?

I would like to see more leukemia related information on mainstream media. There is only so much we ourselves can do to raise awareness on our smaller social media accounts.

When baby Azalea and her parents were all over the media last year during their battle against this awful disease, the numbers on the UK donor register sky rocketed. This legacy will no doubt be a comfort to her parents, even if only a small one. Both, my first and second choice stem cell donors, are from Germany, where 40% of all volunteer donor cells come from. The German register has almost 10,000,000 donors, as it is widely advertised and medical professionals across all sectors urge their patients to sign up. I would love to see that happen.

UPDATES FROM ALAN

CARER EXPERIENCE SURVEY

We, along with CML Advocates Network, and CLL Advocates Network have launched our Carer Experience Survey to guide the changes towards better support for carers.

We believe the powerful voice of lived experience being used as a fuel to drive decision making and change, has the greatest impact on the community.

We value your voice and opinions. Simply fill in the survey here to help guide the future for those affected by Leukemia. We look forward to seeing what you have to say on the matters that we feel matter most!

FOLLOW US !

World Leukemia Day is fast approaching, and with that comes a great chance for us and many of you to connect together online.

As we mentioned earlier in the newsletter, the power and ability to share online is something we believe we should revel in. Social media presents as a gift for us to connect and support those who most need it, we will be share a lot of things as we approach the 4th of September.

Feel free to check into our socials, follow us and get involved.

Facebook: @ALANacuteleuk

Instagram: @alan_acuteleuk

LinkedIn: @acute-leukemia-advocates-network

Twitter: @AcuteLeuk

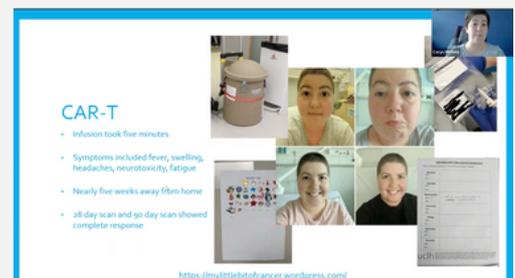
CATCH UP ON CAR-T

At the end of June we ran a webinar around CAR-T therapy, giving a patients perspective and the run down of what this exciting and fast moving treatment offers and the effects it can have.

We were lucky to be joined by Lymphoma Coalition and two patients who shared their experience going through the CAR-T journey.

Feel free to check it out here.

We hope you find it as insightful as we did.



JOIN ALAN

As we continue to expand the global connections, we would like to show you more ways you are able to join the team and advocate for the cause along side us. It is clear that more needs to be done for acute leukemia, and you can help us do that. Find out more by visiting our website. It is time to leave a mark on this planet, to ensure the lives of others are positively impacted by that.

FOR MORE VISIT: <https://acuteleuk.org/>



UPDATE FROM EHA

Austria, Vienna

We were lucky enough to attend the first in person conference for us since the global covid-19 pandemic. It was wonderful to meet with new and familiar faces once more.

The event saw us attend some interesting seminars on new thoughts and processes in leukemia, as well, as holding our highest attended members and supporters meeting to date. .

You can read the full reports from the weekend at EHA over on our [website](#).

READY, SET, ADVOCATE!

We have created a bundle of resources to help you stay vocal during World Leukemia Day, but also through out the year. We know it can be hard sometimes to create content or find information, and so have done it all for you. We are a community, and one we want to help.

You can find our full resource packs to help you give the best help, advice and support #WLD and #BeLeukemiaAware efforts on our [website](#).

WLD TALKS

Last year we saw great success in sharing the story of those affected by Leukemia, via video interview that we recorded virtually.

We feel as an advocacy network it is important that we honour and represent the voices of everyone globally and this form of content gave us a great chance to do so.

This year we will be continuing these interviews and have started to bring you some already.

You can check out this personal insights and stories on our [website](#).

WHEN WILL YOU HEAR FROM US NEXT?

These newsletters will continue every quarter. You can find us on all our major platforms, whilst receiving this straight into your inbox.

If you have anything you would like to be included in one, then please get in touch so we can consider it to be published.

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