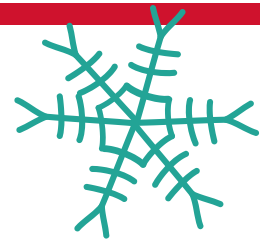


Leukaemia Matters



Winter edition 2023



**Vaughn Scott:
My mission to
raise awareness**

Read more on page 16

**A dedication for our
loved ones**

Read more on page 18

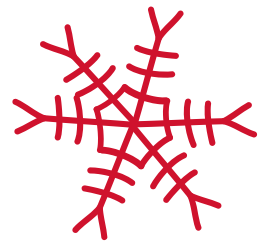


Our free quarterly patient magazine
www.leukaemicare.org.uk



Leukaemia Care
YOUR Blood Cancer Charity

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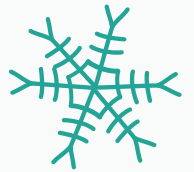


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Hello,

Welcome to our Winter edition of Leukaemia Matters!

In this edition, we feature stories from the likes of Tracey, who marked the end of her eighth round of chemotherapy by buying 'Guardian of the Ocean' at the Unicornfest Auction.

We also catch up with myelodysplastic syndromes (MDS) patient Kes, who celebrates her seventh rebirthday after a stem cell transplant that saved her life. We also met with the likes of Vaughn, who has been using his story to raise awareness of leukaemia, especially amongst the Black, Asian and Minority Ethnic (BAME) community.

Our 'In Conversation With' series continues as we spoke to Dr Shafeek, a leukaemia, lymphoma and myeloma specialist who was faced with his own shocking diagnosis. He discusses his own journey and how this impacts how he cares for his own patients.

As we wrap up another year, it is a great time to reflect on all of the successes we have achieved as a charity - successes that are only made possible by your support, contributions and donations. Thank you to all who have supported Leukaemia Care this year, and we look forward to sharing what we have in store for 2024.

Remember, it is more than okay to reach out if you need support. Call us on our FREE helpline on **08088 010 444**, email us at support@leukaemiacare.org.uk or message us on WhatsApp at **07500 068065**.

If you're reading this issue in a hospital or GP surgery, you can sign up to receive your own free copy of Leukaemia Matters magazine. Just call **01905 755977** or visit our shop [here](#).

We wish you a wonderful festive season, and I look forward to sharing more with you in the New Year.

Chris Matthews-Maxwell
Chairman



CEO Report: The end of an era



We are sad to announce that our Chief Executive, Zack Pemberton-Whiteley, has left Leukaemia Care to take up a new role.

Zack joined the charity in 2014 and prior to his appointment as Chief Executive in 2020, he held the post of Director of Patient Advocacy where he led the charity's range of advocacy and patient support functions. Zack led Leukaemia Care through a significant period of change, including its response to the COVID pandemic, the launch of a new strategic plan, the growth of our fundraising activities and the delivery of several new campaigns and services.



Zack said: "It has been a pleasure and privilege to serve as Chief Executive for these last three years, and in various roles before that. I am extremely proud of all that we have accomplished and to see the organisation thrive and grow each year. I am confident that Leukaemia Care will continue to be an increasingly strong source of support for people affected by leukaemia."

Chris Matthews-Maxwell, Chairman of the Board of Trustees at Leukaemia Care, said: "On behalf of everyone at Leukaemia Care, I want to thank Zack for his tremendous contribution to our work over the last nine years. During Zack's time as Chief Executive, the charity has undertaken a period of transformation and growth, none of which would have been possible without his dedication and leadership."

A warm hello from the both of us as we wander towards the colder snap of winter. You may be thinking that the pictures in the top right look a little different – and indeed, they do.

Since our last edition, our now former Chief Executive Officer Zack Pemberton-Whiteley has left Leukaemia Care after nine years at the charity for a new role. His dedication to the cause has left an indelible mark and he has overseen great change at the charity, driven by the knowledge that there are just so many people out there who need our support.

We want to thank Zack for everything he has given to Leukaemia Care and whilst we seek our new CEO, we will continue to steer the ship. We cannot fail to remember that amidst this transition, our fundamental mission remains unchanged – to continue providing crucial services for patients, caregivers, and loved ones.

Even though faces may change at the helm, the heart of our charity stays the same. As we navigate this shift, we want to assure you that the core of our

purpose, our dedication to serving those in need, remains unwavered.

Join us in acknowledging the departure of our CEO while celebrating the enduring spirit of our organisation. In the face of change, we find strength in our commitment to making a meaningful impact on the lives of those we help. The journey may evolve, but the essence of our mission persists – to offer vital support to those who rely on us.

If you are a new reader of our magazine and thinking you could benefit from the work that we do, then please reach out.

Or if you feel like you could get involved in the vital work we do, you can find out more [here](#).

Warmest wishes,

Monica Izmajlowicz and Nicole Scully
Interim CEOs at Leukaemia Care

Updates: The latest on vaccinations

Everything you need to know from the flu jab to the shingles vaccine and COVID-19 lateral flow testing.

The flu jab

You may be wondering whether you should consider having the flu jab now the weather is colder. The quick answer is yes. If you have any type of blood cancer, it is recommended you should have the flu vaccine as your immunity can be lowered as a result of a diagnosis. Even if you are not currently undergoing treatment, you should still speak to your GP or medical team about the jab.

"I'm worried about my lowered immune system."

It is important to remember that the flu jab does not contain any live virus, so you will not develop the flu after it. However, if you have had a reaction in the past, you should not have this vaccination.

"I had the flu jab last year, do I need it again this year?"

Yes. Viruses that cause the flu can change each year. If you were to skip this year's vaccine, you may be at risk of catching another strain of influenza virus that you have not been vaccinated against.

"How do I get the flu jab?"

Flu vaccine clinics started running from the end of September. Speak to your GP about clinic times. Alternatively, if you are visiting hospital regularly, you might be able to have the vaccination there.

For all the latest information on the flu jab, head over to our blog [here](#).

The shingles vaccine (Shingrix)

Since September 2023, the eligibility for the Shingrix vaccine was expanded to all UK nations. It is now available to all those who are immunocompromised and aged 50 and over. In addition to this update in eligibility, anyone aged 18 to 49 who is due to undergo a stem cell transplant or CAR-T therapy will also be able to receive the vaccine.

"I think I am eligible for this vaccine, how do I get it?"

In the first instance, we recommend you contact your GP or your primary care. You may have already

received an invitation to access the vaccine, whilst others may have to request it.

We would recommend speaking to your GP and asking them if they are offering the vaccine to eligible individuals. It may sometimes be necessary to also speak to your Haematology Team, who may be able to provide you with a supporting letter to share with your GP.

Read all the latest about the Shingrix [here](#).

COVID-19 and changes to lateral flow testing

It was announced that from the 6th November the method of accessing free lateral flow testing would change. Up until then, people were able to access free lateral flow tests (LFTs) by ordering them via the government website or by calling NHS 111.

Instead of this, LFTs can now only be picked up by eligible people or their representatives at the pharmacy.

"Am I still eligible for free LFTs?"

There have been no changes to who can access LFTs. LFTs will still be provided to the same cohort as those who are eligible to receive COVID-19 treatments.

For a recap on the full eligibility for LFTs and how to prove this, read our latest blog [here](#).

Have you got questions about anything you have read in this article? Why not drop us a message on WhatsApp! Message us via the app on **07500 068065**. Alternatively, you can call the helpline on **08088 010 444**.

Updates: Drug approvals you need to know about

The National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) has kept us busy once again with plenty of announcements across the UK.

11th September

Leukaemia Care successfully campaigns for equal access in Scotland to new treatments for chronic lymphocytic leukaemia (CLL) patients.

The SMC announced the approval of ibrutinib in combination with venetoclax on the NHS in Scotland for CLL patients. Following the announcement of the approval by NICE, Nick York, Leukaemia Care's Healthcare Liaison Officer and a CLL patient himself, said "Today's announcement marks a significant moment towards improving the quality of life and survival of people living with CLL in Scotland. These combination therapies do not carry the risks associated with traditional chemotherapy used as first treatment." Read the full update on our website [here](#).

14th September

Leukaemia Care and MPN Voice join forces to successfully campaign for new polycythaemia vera (PV) treatment.

We were pleased to share that NICE approved ruxolitinib treatment for use on the NHS in patients with PV in England. For this treatment appraisal, Leukaemia Care collaborated with the charity MPN Voice to provide evidence on patient experience and outline the case for this treatment to be approved. Find out the details of this announcement [here](#).

9th October

We successfully campaigned for access to potential curative treatment for adult acute lymphoblastic leukaemia (ALL) patients in Scotland.

The SMC has announced that CAR-T therapy will now be approved for use on the NHS in Scotland. It will be used to treat eligible patients with ALL who are over the age of 25. Everything you need to know about this announcement can be found [here](#).

New treatment in Scotland for patients with cytomegalovirus (CMV) was approved.

The SMC has announced the approval of maribavir (Livtency), a new medicine for adults with a post-transplant CMV infection that is resistant to current treatments. We are very pleased that patients in Scotland now have equal access to maribavir as those in England, Wales, and Northern Ireland. For the full announcement, head over to our website [here](#).

20th October

We successfully campaigned for nationwide access to new CLL treatment.

We were pleased to share the decision by both NICE and the SMC to approve zanubrutinib treatment for use on the NHS in patients with CLL in all nations of the UK. NICE and the SMC decided to approve zanubrutinib as they understood that having more treatment options for CLL patients is beneficial and the treatment was deemed cost-effective enough to meet the criteria for approval on the NHS. Full details on this announcement can be found on our website [here](#).

If you would like to know more about any of these announcements, our Advocacy Team is here to provide you with the information and advice you need. Contact the team by emailing advocacy@leukaemiacare.org.uk

LC News

As we wave 2023 a farewell, here are the latest updates from the final few months.

We raised £30,000 during Blood Cancer Awareness Month

Throughout September, we received £19,000 in donations, which was matched up to the value of £10,000 from an anonymous donor bringing the total raised to just under £30,000! We want to say a massive thank you to every single person who donated, as well as our anonymous donor for their generous gift. It's because of your donations that we can continue raising awareness and supporting those affected by a diagnosis.

Making our mark at the Labour Party conference

Our Advocacy Team, along with Leukaemia UK, attended the Labour Conference where they met with the Shadow Secretary of State for Health and Social Care, Wes Streeting MP, and other party members to discuss the challenges in measuring earlier diagnosis rates of leukaemia and shared our policy recommendations. We are determined to put #SpotLeukaemia at the forefront of policymaker minds and will continue to raise awareness of this life-saving campaign.

We made it to Parliament!

Along with over 120 Leukaemia Care supporters and volunteers, the LC team and trustees took a trip to Parliament to talk all things awareness, support and to celebrate how far we have come. We were thrilled to be joined by Mark Tami MP who hosted our event in UK parliament to celebrate and say thanks to our wonderful patients, volunteers, clinical nurse specialists, and pharmaceutical companies that support our cause.

It was great to see so many familiar faces and hear about the difference our support services have made to those affected by a leukaemia, MDS or MPN diagnosis.

Find out more about our trustees (pictured right) [here](#).



A final farewell to our unicorns

We officially bid farewell to our unicorns at the Farewell Festival and later the auction (pictured right) that took place on the 5th October. Our unicorns have now settled into their new homes, and we have enjoyed hearing the stories of how they are making an impact in their local communities. Why not read the full story of 'Guardian of the Ocean's' journey to their new home at Lusty Glaze Beach by turning to page 8.

As a result of the auction, we were able to raise a mammoth £144,880 and we could truly not be any more grateful. Thank you to every single person who designed and created our blessing, who visited the trail in Bristol over the summer, volunteered at the events or in our shop, or donated as a result of the trail. Without you, none of this would have been possible.

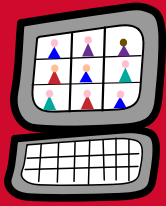


Want to ensure you're always up to date with the latest news?

Sign up for our e-newsletter so all the latest updates land straight in your inbox each month! Sign up [here](#).

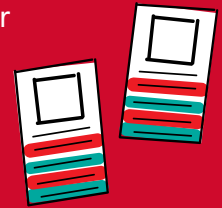
LC 2023: A year in a page

As a charity, we keep patients and their families at the forefront of our minds in everything we do. So as the year draws to a close, let's take a moment to reflect on what we have been able to achieve.



We ran **407*** support groups over the course of the year, giving patients and their loved ones a community to confide in.

Our Buddy Coordinator matched **154*** patients to buddies, helping friendships and companionships blossom.



Our Support Team gave advice to **1,290*** people through our helpline, supporting patients and their loved ones through both the emotional and practical impact of a diagnosis.



We received **843*** enquiries on WhatsApp, allowing our Advocacy Officer to give advice on a range of topics.



807* patients and families received our Cost of Living Fund, which helped to alleviate some of the financial burden that can be accompanied by a diagnosis.



68* patients or their loved ones received professional counselling as a result of our counselling service to help nurture their mental health.

But, it hasn't just been the LC team that has put the work in, our fabulous volunteers and fundraisers are the reason we can make any of this happen.

At our Parliament event, we were delighted to hold our volunteer award ceremony. We would love to take this opportunity to thank each and every person that joined us to celebrate. And of course, a special thanks to our winners:

- **Listener of the Year** - Mandy Kerr
- **Fundraising Champion** - Brian Bennett
- **Patient Champions** - Colin Heyes and Margaret Stirling
- **Medical Champions** - The Haematology CNS Team at Royal Gwent and Nevill Hall Hospitals (pictured right)
- **Newcomers of the Year** - Meryl Simons and Lynette Dudley
- **Everyday Hero** - Ross Happell



*Statistics collected from 1st January to 31st October 2023.



Tracey Griffiths: The Guardian of Lusty Glaze

Celebrating the end of treatment is a momentous occasion, so what better way for Tracey to celebrate other than purchasing her very own unicorn from the Unicornfest trail.

I completed my eighth and final round of chemotherapy on Unicornfest's auction night. So, instead of ringing the traditional end of treatment bell, I supported Leukaemia Care by buying my very own unicorn!

During my treatment, I saw others ringing the bell, marking the end of their chemotherapy sessions. But for me, I didn't feel ready for that moment because it didn't symbolise the end of my journey. It marked the completion of one phase, but there were still challenges ahead. I was happy for those completing their treatment and but felt a sadness for those who wouldn't have the chance.

In my search for a meaningful way to commemorate this moment, I came across a beautiful two-metre tall unicorn sculpture, the 'Guardian of the Ocean,' painted by the talented artist Farrah Fortnam.

At the Unicornfest auction held in Bristol, I purchased the unicorn for £3,400.

The 'Guardian of the Ocean' has now found its home at Lusty Glaze Beach in Newquay, a place deeply connected to my spirit and love for the ocean. I chose this magnificent creature as a symbol of strength and resilience. It embodies the fighting spirit that has kept me going throughout my journey.

Lusty Glaze Beach, with its vibrant community and positivity, is the perfect setting for the 'Guardian of the Ocean.' We invite visitors to take photos with the unicorn and share them on social media using the hashtag #LustyUnicornForLeukaemiaCare. By doing so, we hope to raise awareness and funds for Leukaemia Care, a charity that provided me with crucial support during my diagnosis.

I am immensely grateful for the unwavering support of my family, friends, and colleagues who have stood by me throughout this challenging time. A special thanks goes to the dedicated team at the Haematology Unit, Royal Cornwall Hospital Trust, and the Headland Unit. Their support has been my strength.

I'm excited about the future and the opportunities we have to create magic with our 'Guardian of the Ocean.'



New year and a time to make new connections

Tracey signed up to our Buddy Scheme to speak to someone who had experienced what she was going through.

"Rory, my buddy, has been incredibly supportive, and I am grateful for all the advice and check-ins we've had."

If you too could benefit from talking to someone, or perhaps want to support someone throughout their own journey, we would love to hear from you.

Head into 2024 by connecting with others. Click [here](#) for more information.

Naa Yeye: My twentieth birthday

20 years after her diagnosis, Naa Yeye is sharing her story to raise awareness of the effects a leukaemia diagnosis can have on someone in the BAME community.

I was just 18 when I received the life-altering diagnosis: acute lymphoblastic leukaemia (ALL). My life was only really just beginning before it came to an abrupt halt. That's why I want to share my story; I want others to not feel alone in their own journey, especially those from Black, Asian and minority ethnic backgrounds.

It started with lumps under my armpit and bruising. After numerous visits to the GP, I collapsed in the shower on 27th December 2003.

Rushed to the hospital, I just remember thinking, "Will I lose my hair?" and "What's going to happen now?".

And so began my eight-month hospital stay, filled with chemotherapy, radiotherapy, and the uncertainty of a stem cell transplant.

My brother, Duncan, became my stem cell donor. I have five brothers and sisters, but I wasn't surprised it was him; we do look the most alike!

After the transplant, physical recovery was a grueling process. From being bedridden to learning to walk, breathe and eat independently, was a challenge. I vividly remember the first thing I could taste after my transplant – a kebab. It marked the return of my senses and a sense of normalcy in my life.

Emotionally, it was taxing. While psychological support was available, I found solace in the unwavering support of my family and friends. My hospital staff became my second family, pulling me through the lowest of days.

The aftermath of the transplant wasn't easy. Graft versus Host Disease (GvHD) of the mouth brought its own set of challenges, making even eating a painful task. My lips have been the most affected – I don't feel any pain, but it has had a massive effect on them. People stare, but they don't understand

what I've been through. Fatigue often creeps in too, but in order to stay awake I go for walks.

My support system have played a pivotal role in my recovery. Angela, my healthcare assistant, helped me on my lowest days when my family weren't around. We used to play old school garage to help lift my spirits when I needed it the most. The other nurses would come in and dance; we had good times!

My motivation now is to be the voice that was absent when I needed it most. As a black woman, finding someone from a similar background sharing their leukaemia journey was nearly impossible. I aim to change that. My YouTube channel is my way of reaching out, not just to BAME individuals, but to anyone with a cancer diagnosis. I want them to know they are not alone. Disabilities, I've learned, don't hinder; they add 'extra spice' to life.

My 20-year transplant anniversary is approaching, and the milestone fills me with a profound sense of accomplishment. Five years brought joy, ten and 15 years brought relief, but 20 years? It's a testament to the strength of the human spirit. In sharing my story, I hope to inspire others who have been going through just the same.

Do you know someone who could make a life-changing donation?

For someone with blood cancer, a stem cell transplant could give them a second chance of life. If you know someone who is able to join a register, signing up is easy. They can do this via:

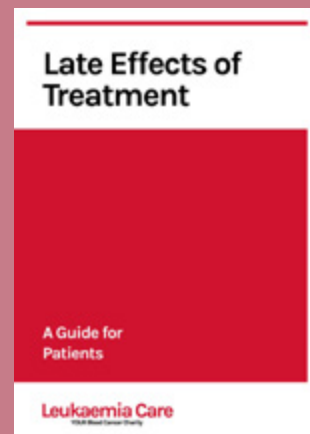
- **Anthony Nolan** (for those aged 16 to 30 years old)
- **DKMS** (for those aged 17 to 55 years old)



Want to know more about late effects such as fatigue?

Some side effects of treatment do not occur for months or even years after treatment ends. These side effects are called late effects and can be physical or emotional. Our Late Effects of Treatment booklet is designed to provide you with information about the late effects you may experience, what to expect and how they may be managed.

Get your free online or hardcopy information booklets on our shop, which you can find [here](#).



Mark Corbett: the climb to Everest

Mark took on the challenge of a lifetime to raise money for Leukaemia Care. Here, he recounts his journey to the top of Everest Base Camp and all the hurdles that came along with it.

18,000 feet. 14 days. Mount Everest. All for Leukaemia Care.

On the 21st October, I began my trip to reach Everest Base Camp. I flew to Kathmandu, the capital of Nepal, before taking another flight to Lukla. Lukla is home to one of the world's most dangerous airports, but it was also where I began the 150km trek through the Himalayas.

Many will share the joys of the challenge, but I can only be honest. The trek to Everest was grueling, and the hardest thing I have done in my life. I'm not great with heights, so I faced my fears daily, whether that be travelling across a bouncy suspension bridge or walking on narrow trails with a drop of several hundred feet right along the side of it.

When the day of trekking came to an end, we were of course not met by a five-star service. We slept in little, cold lodges and by day three we had no warm water to shower in. So, wet wipe washes were the next best thing. Even sleeping was a tricky task; as the altitude rose, there was less oxygen, so a good night's rest was never on the cards.

But then you get that lump in the throat moment. Day three was the first day we looked out and could see Everest. No matter where you looked, the scenery seemed as if it had been taken straight out of a postcard, and it gave me another reason to push on.

I took each day one at a time, not even really thinking of the end goal until I was a couple of days away from it, knowing only severe altitude sickness would stop me from doing it.

Day eight - base camp day was special. We set off in the freezing cold morning and got there at 9:22am; a time and date I'll never forget. It was eerily quiet, other than being able to hear the glacier cracking loudly every few minutes.

We stayed for around an hour, before setting off back down.

Climbing to Mount Everest Base Camp was a huge challenge and not one I took lightly. The training and preparation for the trek was relentless. But there was a good reason I was doing this.

I think everybody will have at some point in their lives known someone affected by leukaemia. It can affect anyone, at any point in their life.

As a family, we have been touched by leukaemia twice. Firstly Joe, the son of family friends who lost his life to acute lymphoblastic leukaemia (ALL) at just 20 years of age. And secondly, my mother-in-law Shirley, who lost her life to acute myeloid leukaemia (AML).

Shirley was so incredibly brave and strong throughout her illness, but sadly lost her life in June of 2022. She was one of life's good ones; positive, always busy and had a huge influence on my own children when they were growing up. She was even one of the first to donate when she found out I was taking on this challenge.

On day seven of the trek, I was able to put a photo of Shirley and Joe's tie that our friends had given me on one of the memorial stones at the Everest Memorial. On the way back down, I was able to stop back off there just to let them know I had done it.

I'm still not over the challenge; I'm worn out and feel as if I'm on a comedown. With these experiences, everyone will always share how amazing it is - which of course it was - but not how it can feel when it's all over. I want to share the reality.

I've spent 18 months planning it, training for it, and thinking about it several times a day, so to go from that to nothing, I don't really know what to do with myself at the minute.

But perhaps when the dust has settled, another challenge could be on the cards...

If you're a friend or family member of someone who has received an acute or chronic leukaemia diagnosis, you can join one of our dedicated support groups. You can find out more [here](#).



Mark has raised a whopping £2,809 and counting!

We would love to say a massive thank you to Mark for his incredible commitment to raising money for Leukaemia Care. Every day, we are amazed by the lengths people like Mark go to towards helping us continue supporting those affected by a leukaemia, MDS or an MPN diagnosis.

Do you fancy taking on the challenge of a lifetime in 2024? We'd love to talk to you about it! Let us know what sort of challenges make you tick and let's start your fundraising journey today, together. Drop us an email and tell us what you've got in mind by contacting fundraising@leukaemiacare.org.uk

Marine Tullet:

My brother's story

After her brother received a terminal diagnosis, Marine and her family decided to investigate the world of clinical trials, compassionate use and what they can offer. She posted on LinkedIn, tagging pharmaceutical companies with a post that gained over four million views.

In February 2022, my brother was diagnosed with acute myeloid leukaemia (AML) with a TP53 mutation and extramedullary disease.

A few days before his diagnosis, he experienced severe back pain, fatigue, petechiae and brown spots on his chest - something we later found out to be leukaemia cells. After consulting an osteopath and a GP, a blood test was ordered. A few hours later, the doctor called him telling him to go to the emergency room at the hospital. The next day he was diagnosed with AML.

Just five days after his diagnosis, the first round of chemotherapy commenced. We knew that multiple rounds of chemotherapy and a potential bone marrow transplant were in store. One of the peculiarities of leukaemia is the isolation of both patients and their families. In the corridors, we didn't see anyone apart from a few nurses and doctors. During each round of chemotherapy, my brother had to stay sterile in a room for at least five weeks.

A month and a half passed, and the results after the first round of chemotherapy indicated that my brother's marrow was clean and that they had managed to reduce the rate of leukaemia below five per cent.

However, the spots on his chest began to return, meaning the leukaemia was still active and progressing. As a result, the second round of chemotherapy was not a consolidation chemotherapy as planned, but in fact a salvation one.

My brother went through four intensive chemotherapy sessions like this. He unfortunately relapsed during the two weeks of rest imposed between each chemotherapy.

The most difficult relapse was after the third round where he had severe facial paralysis and lymph nodes. Examinations were carried out to confirm or refute possible neuro-meningeal invasion, which was never explicitly proven by exams. It was also a difficult relapse because the doctors told us that he had no more possible treatments.

For a week we were all at home thinking there were no more options. After insisting with the doctors (and because my brother was young), the doctors finally offered a fourth chemotherapy line.

Even after the fourth chemotherapy, there was a relapse, so it was decided my brother would have a bone marrow transplant. We knew there was little chance it would work, but we had to try. It was our last hope.

The transplant took place on the 25th September and went well. Two weeks later, he was able to go out and I put him up in my apartment. However, one-month post-transplant, the disease unfortunately returned. My brother didn't tell me at first, but I saw his behaviour change; he became worried and sad. We then understood that the leukaemia had relapsed, and quickly.

Doctors stopped immunosuppressants in a short time to cause Graft versus Host Disease (GvHD). The objective was to allow the graft to take up more space and establish itself in the body. At the same time, my brother had outpatient chemotherapy; more palliative than curative.

I began reading research articles and looking for clinical trials, something I had heard about upon this journey. The darkest period began. In mid-November, I took sick leave so I could tirelessly research clinical trials.

I had a range of doctors on the phone or by email in France, but also in Germany, Spain, Italy, and

the United States. We had a few leads, I sent my brother's file but nothing was ever concrete. My brother's case was not of interest, for reasons such as the mutation or that the transplant was less than three years old.

Just before Christmas, my brother's condition continued to deteriorate, so we made a LinkedIn post. I posted it on my profile tagging the pharmaceutical companies where I had seen interesting clinical trials. The post did well; it got four million views and I received more than 1,000 emails. Our research was able to broaden.

We had a strong lead for Magrolimab developed by Gilead Science. From the beginning of January to mid-February, there were discussions with Gilead to get the drug in compassionate use. A patient association helped me a lot in the negotiation. We had three refusals with unclear reasons before finally having a positive answer from Gilead which they wanted to remain secret. Unfortunately, they gave a response too late when my brother was already in sedation.

The problem with compassionate care is that the legislation is specific to each country and the access process is not clear. In addition, in France, there are commitments that the laboratory must make which risk impacting the planned development of its drugs.

At the same time as this fight, my brother was waging an even more intense one against his leukaemia. At the end of December, he had a severe stomach infection which forced him to be re-hospitalised. His condition was critical according to doctors. Unfortunately, the infection could never really be controlled. At the end of January, we were lucky enough to have him at home for a week; a very difficult week but one where the four of us were able to share valuable moments.

His condition became worse and my brother was placed in palliative care on the 10th February 2023. Six days later, I lost my brother.



In our advocacy efforts, we collaborate with various organisations to amplify the collective voice of cancer patients. These coalitions leverage the expertise and influence of their members to advocate for patient interests in diverse areas. As a member of several UK, European, and global organisations, we strive to represent the perspectives of blood cancer patients comprehensively. Find out more [here](#).

An in-depth dive into AML

AML is a blood cancer of the bone marrow's myeloid cells. It is an acute leukaemia as they develop rapidly and is an aggressive type of leukaemia. It is also the most common type of acute leukaemia representing 80% of cases in adults and 15% to 20% in children.

Being diagnosed with AML can be a shock, and finding both correct and relevant information on your, or your loved one's diagnosis can feel tricky. Our booklet covers the basics, such as the causes, who it affects and likely treatments. Read the latest information on AML from our booklet [here](#).

Vaughn Scott:

My mission to raise awareness

Vaughn was 32 and working overseas for the Armed Forces when he began to experience chest pain. Soon after, he was medically evacuated back to the UK to be diagnosed with acute lymphoblastic leukaemia (ALL). He shares his journey, and the importance of raising awareness, especially amongst the BAME community.

Raising awareness of the signs and symptoms within the Black community has been one of the most important things I have taken from my leukaemia journey. So many of my friends and family had no idea things were so much more difficult for people of our ethnicity and the fact we have been able to help so many more people like me is amazing.

My name is Vaughn, and in 2018 my life took an unexpected turn.

It started with a dull pain my chest, which escalated into excruciating agony. I was working overseas as a part of the armed forces. After a series of tests, the on-board doctor told me I should get off the ship for the nearby military hospital.

At the hospital, they carried out blood tests, CT scans, chest x-rays and pericarditis (fluid around the heart) was confirmed. After a couple of days another CT scan was done which showed the pericarditis was now forming around the lungs, and it was at this point they said I needed to get back to the UK as soon as possible.

Back in the UK, my journey through the labyrinth of treatments began. At first, the doctors suspected a viral origin for my condition, placing me on an infectious disease ward. However, my condition worsened and my diagnosis was confirmed as ALL.

Despite my diagnosis, I was thankful to have the support of the incredible medical team and my

newfound friendships with fellow patients in the wards.

The hunt for a bone marrow donor soon began, and we started to understand the difficulties of finding a suitable donor, especially given my BAME (Black, Asian and Minority Ethnic) background.

Faced with daunting odds, my family and I embarked on a mission to raise awareness about the critical need for more diverse bone marrow donors. We organised events, registered people, and rallied support, eventually finding a match in two umbilical cords from the USA. The transplant, though not without complications, marked a pivotal moment in my journey.

The aftermath, including my experience with Graft versus Host Disease (GvHD) was tricky; I was unable to eat for weeks whilst dealing with various infections, fatigue and the emotional toll of it all.

But now, more than five years post-transplant, my life has entered a new chapter. I am still adjusting to the 'new normal' and facing the misconceptions of my invisible struggles.

I have the most tremendous thanks to the Lord Jesus for his healing power in my life. With his help, I am going from strength to strength; with no complications. I have the peace that all is and will be well in the future.

For those out there reading this who are experiencing their own or a loved one's diagnosis journey, I want you to know there is hope. This is just another of life's hurdles!



Can you help to raise awareness like Vaughn?

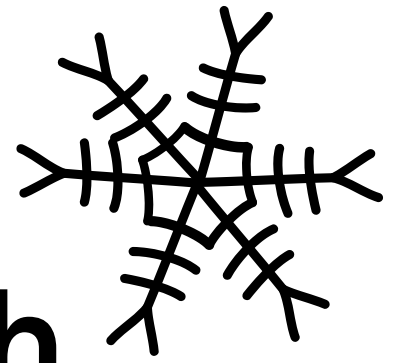
There are a million and one different ways to get involved to raise awareness or support others in the blood cancer community. 2024 is looking to be a big year for us, and we would love to have you on board.

We have plenty of volunteering opportunities to get stuck into, but if you have something else in mind, we would love to hear about it!

View our pre-existing opportunities [here](#).

Or, drop us an email at volunteering@leukaemiacare.org.uk with your ideas, and our team will be in touch.

Janine Black: My Christmas wish



Janine was diagnosed with acute myeloid leukaemia (AML) just two days before her 55th birthday. What she didn't know was that she would spend the coming Christmas and New Year in hospital too. This Christmas, Janine shares her story to raise awareness of the impact Leukaemia Care has had on her, and how we can support you this festive season.

Like for many, Christmas is an important time for me and my family. A chance to come together, push worries aside and celebrate. But, Christmas hasn't always been like this. In 2019, I spent Christmas and New Year in hospital – the very same one where I spent my working life as an optometrist looking after others. And then those four dreaded words came - "It's acute myeloid leukaemia".

As well as the breathlessness, my gums felt sore, and then I developed a flu-like illness and dry cough. I developed lumps under my armpits. I was given antibiotics and sent for a chest X-ray which was clear. I then visited the doctor a second time as the cough persisted and my breathlessness was getting worse. This doctor organised an ECG and blood tests for the following week. Climbing stairs became very difficult and I would fall asleep as soon as I got home from work.

At this stage, my colleagues noticed that I was pale and losing weight. I had lost my appetite too. After a particularly bad coughing fit, I developed a large black floater in my right eye. My optometrist colleague discovered that I had Roth's spots in my eyes; unusual haemorrhages with white centres.

My colleagues urged me to go back and the second GP gave me a thorough examination and found that I had a racing heart and high blood pressure. She arranged blood tests and an ECG for the following week.

I was admitted in the early hours and a registrar examined me alongside a trainee doctor. The registrar asked me how much I knew, and I responded by blurting out the words "Have I got leukaemia?" My worst suspicions were confirmed; it was AML.

I held my daughter Hannah in my arms, wondering if this was the last time I would do so. What was going to happen?

An unbearable weight sat on my shoulders; feelings of guilt and isolation started rising and I didn't know who to turn to.

This was until I found Leukaemia Care.

Leukaemia Care have been a lifeline throughout my journey. I was fortunate to receive a financial grant from the charity's Counselling Service, along with my daughter, which allowed us both to seek expert help. Dealing with my symptoms, medical appointments, diagnosis, as well as treatments and shielding on top, had really taken its toll on us both. The fund helped me to manage my feelings of anxiety and get through a really scary time. That's why I know a donation from you today will enable others like me, living with leukaemia, to turn and find Leukaemia Care this Christmas - ready and waiting to help in so many ways.

I also benefited from Leukaemia Care's Buddy Scheme. It's such a fantastic idea which matched me with a fellow patient with the same diagnosis, so we could chat together. My buddy Jude understood exactly what I was going through. We speak regularly, meeting up too – it's hard to explain just how much she's helped me through my treatment. A service only made possible through kind donations like yours.

I've also been very grateful for Leukaemia Care's specialist nurses when times were hard; the support groups which meant I didn't feel alone in what I was dealing with, and the informative webinars supplying me with appropriate and accurate information to guide me through an awful time. Now I feel less isolated, surrounded by uplifting people.



Having been through what I have, Christmas time to me is for reflection and being thankful for the place I'm now in – and I credit much of that to the support of Leukaemia Care and generous people like you. My journey could have been very different.

Your gift today will allow more people like me to receive this incredible level of support, free of charge, when they most need it.

My story may sound all familiar, and your donation might be in recognition of someone whom you are immensely proud of, currently living with a diagnosis. Perhaps, that's you! Or, in remembrance

of your loved one, you'll donate, honouring and thinking of them even more so at this time of year.

I can't thank you enough for considering to contribute and for showing Snow Much Love – you really can make a difference to the lives of those, like me, living with leukaemia, myelodysplastic syndromes (MDS) or an myeloproliferative neoplasm (MPN) this Christmas. And their families too – which is what Christmas is all about after all.

Wishing you and your loved ones a truly special festive time.



Can you give Snow Much Love this Christmas?

Just £10 can ensure a newly diagnosed patient and their loved ones get the information they need at this difficult time. To donate:

- Head over to our website, and select the amount you wish to donate [here](#).
- Call our office and make a donation over the phone by calling **01905 755977**.

If you can, please consider donating to our **Snow Much Love** Appeal this festive season; your donation could be someone's Christmas wish. Thank you for all the support you have shown us this year. Every single donation makes a huge impact on those living and supporting someone with a diagnosis.



A dedication for our loved ones

"Life is full of grief, to exactly the degree we allow ourselves to love other people." - Orson Scott Card, Shadow of the Giant.

The feeling of loss is indescribable. No matter how much you may feel prepared for the loss of a loved one, you never truly know what to expect.

But in these times, especially in the festive season, it's important to reflect. To reflect on our own personal journeys, our relationships and those around us.

As we close the cover on another chapter of our lives, we want to take this moment to pause, and remember those we have lost.

Throughout the winter, people have been posting tributes in memory of their loved ones that we want to share.

"Mum and Lesley. Both missed so much, especially at Christmas. Always in our hearts."

"Nan Joyce, you will be greatly missed this Christmas and I know Mum will be thinking about you a lot x"

"Dad. This will be our first Christmas without you. We all miss you so much. We know that you wouldn't want us to be sad so we will have fun in your memory and save a seat for you at the table. Xxx"

"A piece of our hearts is in heaven with you Nana. We are privileged to have such special memories with such a beautiful soul. We miss you so much, keep shining bright xxxxx"



For Rob

We also want to pay tribute to Rob Hale, who we have featured twice in Leukaemia Matters. Sadly, Rob died on the 13th November after receiving a terminal diagnosis of acute myeloid leukaemia (AML) last year.

He spread awareness of the reality of living with a terminal diagnosis with us, and the world, for a total of 332 days. His dry humour and candour, which he expressed on his Instagram (@robs_final_dance), created a community where others could share their own experiences. Rob - thank you for sharing your journey with the world.

Our thoughts are with Rob's loved ones at this difficult time.



Our darling Bex

"Our darling Bex, Becky. You were always the shining star of our Christmases. The one who planned food, thoughtful presents, the fun games and made it all happen. We will miss your laughter and excitement. We will try to honour you by being strong as you were so courageous and caring. As always your spirit will be with us. Love you always. Xxx"

Fundraising in memory of a loved one

Rebecca 'Bex' Clarkson suddenly passed as a result of leukaemia in April. Rebecca's employer, Sika, made a donation at the time of Rebecca's funeral but has also been a source of support for her fiancé, and mother Joy.

To raise money in memory of Rebecca, they held their SikaCycle event. 250 plus cyclists completed either a 50 or 100-mile course which was followed by a gala dinner and two night stay in a hotel.

"As Rebecca was an employee of Sika she was fortunate to have a good sick pay package and very supportive company backup. This made life easier and took some of the financial worries away. I realise that this is not the case for many people in this situation and this is one of the reasons why we wanted to have Leukemia Care as the charity." - Rebecca's Mum, Joy.

Sika, alongside Rebecca's family, raised over an incredible £25,000 in memory of Rebecca. We want to say a special thank you to everyone who was involved in this wonderful fundraiser.

Losing a loved one is tremendously difficult, but getting together to remember and celebrate their life can be a great way to support one another. If you would like too, there are many ways you can fundraise in memory of a loved one. Talk to us about your ideas and we can help start your fundraiser by emailing us at bereavement@leukaemiacare.org.uk.

I've recently lost a loved one, who do I turn to?

Finding out your loved one is facing end of life is a big thing to deal with. There is no right or wrong way to feel when receiving this news, and there is no right or wrong way to grieve a loss. But, there are people and places to turn to.

Online Bereavement Counsellor

Our online Bereavement Support Chat allows you to chat directly with an experienced bereavement counsellor between Monday and Friday, 9:00am to 9:00pm. Get in contact [here](#).

Bereavement Support Group

Join a supportive environment, which provides a helpful way to explore feelings and share experiences with the solidarity of others.

All the latest details of the next support group can be found [here](#).

Bereavement Facebook Group

An online community for those experiencing bereavement at any stage. For information, advice and a place to share experiences with others, join the group [here](#).

Counselling Service

A grant of up to £420 to access private counselling services for those who are about to or are already experiencing the loss of a loved one. Access the service [here](#).

Celebrate the life of your loved one

An online memorial page where you, family and friends can remember your loved one and share treasured memories to celebrate their life.

Join a community of others sharing **Snow Much Love** for their loved ones on our tribute page [here](#).

Lesley: When Christmas comes early

Lesley was looking forward to the festive season, but when she began to experience chest pains, she knew that Christmas would not be like all the other years before. Here, she shares her Christmas tale.

Christmas is a special time for my family. So, when I was diagnosed with acute myeloid leukaemia (AML) during the festive season, I was devastated. Would we get to spend this time together as a family?

It all began just after the autumn school term had finished and I was well in the lead up to Christmas. I was a bit tired, but that was quite normal for the end of term. Nothing seemed unusual, although in retrospect, I'd had a cold that I'd struggled to throw off for two months.

It was a Monday evening and I was relaxing in front of the TV when I felt a squeezing pain in my chest. It was bearable, so I just waited for it to pass. The next morning I thought I'd better get it checked out, so I phoned the surgery and the doctor advised me to go straight to A&E.

All the tests were fine until late in the afternoon when I was called in by a haematology registrar. She told me the blood tests had shown there were some abnormal blood cells and a problem with my bone marrow. I needed to go back the next morning for another test. Alarm bells started ringing; my Dad had died suddenly from multiple myeloma many years ago.

The next morning I had a bone marrow biopsy – they suspected leukaemia, and my AML diagnosis was confirmed two days later.

I was 59 – I was considered fit and young, so four rounds of chemotherapy were about to ensue. I was in shock, but I was also strong and determined.

We decided to celebrate Christmas early, just in case I was called in quickly. My Mum was in a care home, so I recorded some video messages for my sister to share with her over Christmas and the New Year. We had a 'Christmas day' the Sunday before, without all the trimmings, but with what we had got so far. We had a simple Christmas dinner, shared some presents and played some games.

The following Tuesday, I went in for my PICC line and was admitted the same day. The COVID-19 restrictions meant no visitors, which was tough.

That first afternoon, a volunteer brought round Christmas cards made by a local primary school. It was a nice touch and went on the windowsill, along with my good luck and get well cards. I tried to find some Christmas carols on the radio, but it was all rather surreal.

Join a community of others for support, like Lesley.

Did you know that we run 65 different support groups and national meetings across the country?

We run a variety of support groups and national meetings where you can meet others who share the same experience, as well as learn from professionals from different backgrounds who attend and give talks on a wide range of topics. There is always a place for you at our support groups, and we would love to see you there.

Find your local or remote support group [here](#).

On 23rd December I started ten days of intensive chemotherapy, but I was allowed to pop home for a few hours on Christmas Day. I felt weak and sleepy, but I was thankful to be home!

After three weeks at home after the first round of chemotherapy, I was back in for my second round. I could feel my positive outlook begin to waver; I felt weak, and treatment was overwhelming.

By now my hair was falling out in handfuls, but the good news was that the first round of chemotherapy had put me in remission.

Round three of chemotherapy came and went, and I was lucky enough to spend my 60th birthday away for the night in a hotel accompanied by some lovely weather.

At the end of June, I was told I would have no further treatment. My bone marrow couldn't take any more, but I was clear of leukaemia. This was finally it - I was on the road to recovery.

Now almost two years since diagnosis, I am well, enjoying life, avoiding stress where possible, eating healthily and being relatively active. Still with a positive attitude and with the love and support of my husband, sister and friends.

Christmas this year will still be the three of us, Mum having sadly passed away in September. But I'm looking forward to it; the laughter, the games and of course all the giving and receiving that comes with it!



PICTURE (ABOVE): LESLEY AND HER HUSBAND GIANNI



Leukaemia Care's Christmas Hours

Being diagnosed or having a loved one be diagnosed during the festive period can sometimes make this time of year feel difficult.

Our helpline will be closed from 12:30pm on Friday 22nd December until normal service resumes at 9:00am on Tuesday 2nd January.

Our nurse will last be available on the helpline on Wednesday 20th December between the times of 9:00am and 2:00pm.

If you do need any support over the Christmas period, the following charities will be available:

Samaritans:

Helpline (available 24 hours a day, 365 days a year): **116 123**

www.samaritans.org

Age UK:

Helpline (available 365 days a year, between 8:00am - 7:00pm): **0800 055 6112**

www.ageuk.org.uk

Macmillan:

Helpline (available 365 days a year, between 8:00am - 8:00pm): **0808 808 00 00**

www.macmillan.org.uk

The Silver Line:

Helpline (for those aged 55 years or over, available 24 hours a day, 7 days a week): **0800 470 80 90**

Shout:

Text service (available 24 hours a day, 7 days a week): text 'SHOUT' to **85258**

Campaign Against Living Miserably:

Helpline (available 5:00pm - midnight, 365 days a year): **0800 58 58 58**



In conversation with: Dr Salim Shafeek



Dr Salim Shafeek had been treating blood cancer patients for 17 years in Worcestershire Royal Hospital until his own symptoms started feeling all too familiar. He spoke to us about his experience of being on both sides of the ward.

Dr Salim Shafeek is an expert haematologist in the West Midlands, specialising in leukaemia, lymphoma and myeloma. He was the former Clinical Director for Haematology and Oncology at the Worcestershire Acute NHS Trust since 2009.

However, in 2019 Dr Shafeek began to experience his own set of symptoms which eventually led him to his own diagnosis of multiple myeloma. He tells his story, and how his journey affects how he treats his own patients.

Thank you for taking the time to join us, Dr Shafeek. Tell us a little about how your myeloma journey begins.

I had been working in Worcester Hospital since 2002 as the leading myeloma specialist, treating different malignancies like leukaemia, lymphoma and myeloma.

In December 2018, I began to experience some discomfort in the back. The pain was coming and going, so I wasn't feeling too concerned.

Around the new year, the pain returned but progressively got worse and worse. I had been working a lot; maybe this was a sign to take a rest. I was the Clinical Director at the time - a job with many responsibilities and little time for rest, so it was no surprise that I had been feeling a little bit achy.

But by early January, the pain was so bad I couldn't bear it. I thought maybe it had something to do with my bed, or perhaps the car seat, but I knew at this

point I should probably book an appointment with the GP.

We couldn't feel any localised problems; we thought it was muscular and I was told to just have some painkillers, so I was feeling quite reassured. But a few days later, it continued to worsen.

More warning signs began to arise in my chest. I knew what these signs could have meant - I'm a doctor! But it is also what I teach my medical students. So, I rang the GP again and told them I had new symptoms coming. I had an MRI scan in the morning, and returned to work straight after.

That was until my phone began to ring - "We have a problem".

I was told more scans needed to be done, and I began to feel really shaken. Something was clearly, very wrong, and everyone knew it too. The staff knew me; I had never had a day off sick.

My colleagues insisted I should have a myeloma screening as well as a CT scan. The CT scan came back all clear, so any other cancer was excluded but I did have some sort of spinal damage.

And then the further scans came back; it was myeloma.

I was referred to my colleagues at Queen Elizabeth Hospital Birmingham; they were shocked to see me as I worked with them previously. More tests were done and it was proved that my spine was in fact critically damaged.

I was told to speak to Dr Sean Molloy; he has a special interest in spinal myeloma and is big in

the industry. We had never spoken directly and it was only by chance I had his name and number on my clipboard. I left him a message, and he rang me straight back in the evening, telling me to see him the next day.

A spinal corset was made for me, and it has saved my life. It is not a standard treatment, but I stick to what he tells me - he knows his stuff inside out.

He told me chemotherapy would also need to start immediately, and if there was no improvement radiotherapy would be my second option. So, it began. I was lucky to have no major side effects - just some shortness of breath, amplified by the corset.

I was thinking of the worst-case scenario, knowing what some of my own patients had been through. My own colleagues knew this; they told me that because I was a doctor I was panicking.

I was referred to a cardiologist to exclude some of the worst-case scenarios, which it did, and my mind was put to rest. I was signed off work and four rounds of chemotherapy ensued before a stem cell transplant. I met some of my own patients there, now from a completely different perspective; a fellow patient, not their consultant. A patient of mine started crying when he saw me, originally thinking maybe it was my wife who wasn't well, not me.

While waiting for my transplant, I began developing severe neuropathy. Suddenly, everything felt textbook. It was so intense, I couldn't believe it. I didn't have any pain, but the neuropathy was bad.

I emailed Professor Kumar at the Mayo Clinic and explained the problem. He was quick to come back to me to tell me that I was definitely on the correct treatment.

After the post-American Conference of Hematology meeting in Birmingham, he came to my house to visit. He knew my dad, who is still semi-practising haematology in India. My dad is old-fashioned

and contradicted every treatment I was having. I had to tell him that this was what everyone was doing in the UK, Europe and the US. But of course, no one could convince my dad!

It sounds like you were able to connect with some great healthcare professionals throughout your diagnosis. What was it like to continue on to the next step of having a stem cell transplant?

My transplant was a significant moment in my journey. I had so many messages of support and encouragement; many of which were from my own myeloma patients.

I received a card from one patient who gave me their own tips and tricks for dealing with the effects of chemotherapy or a transplant; ones that I might not have thought of if I hadn't been going through a diagnosis myself.

A year later, I joined back at work part-time, and am currently on maintenance treatment. Luckily, I hadn't been feeling too bad during and after my treatment, the best thing I did was keep in contact with the team.

I was lucky to have a good sick pay package, so I was still able to support my family. It also highlighted the importance of critical care insurance, something of which I never thought I would have to use in my lifetime.

I also faced the hardships of adjusting to working from, especially throughout the COVID-19 pandemic; it was a completely different experience and environment to what I used to.

Now being a doctor with a real patient perspective, do you think this has changed how you care for others?

Massively. I know what to expect now. I feel better equipped than anyone to empathise with my patients. It made me realise that anything could happen to anybody.

But, I also rediscovered how important family really is. My wife has been a strong support, she is amazingly brave. My son was in his third year in medicine and my daughter had just joined university - they understood the possible prognosis. But with their strength and courage, I just knew I had to get on with it.

How are we supporting healthcare professionals?

We offer a range of resources and guidance to help support healthcare professionals diagnose leukaemia quicker, as well as better care for patients and their loved ones.

From e-learning to our Nurse Bursary Scheme, we have plenty of tools to get you started.

If you are a healthcare professional, or know someone who could benefit from these resources, head over to our healthcare professional hub [here](#).

Barry and Simon: Testing the Limits

What started as a midlife crisis has now turned into a journey of endless giving. Barry and Simon share their fundraising story and their plans for 2024.

Friends and neighbours Barry and Simon took on the Swim Serpentine in 2023, raising over £2,000 for Leukaemia Care. Both had taken on other big challenges before, but felt inspired by others achieving the London Classics Medal, and just knew they had to give it a go.

Barry says...

"Last year, we did the Virtual London Marathon and Ride London event. After completing both events, we noticed people collecting their London Classics medal which looked incredibly impressive to us. Inspired by the thought of getting a medal ourselves, we decided to enter Swim Serpentine and were lucky enough to find that Leukaemia Care could offer us places.

We had not been involved in the charity before, but at the event, we met a lady who had been hugely helped by the charity and even now, I get goosebumps thinking about how much of a difference it has made to her life. So, what started out as quite a selfish act, ended up being rather emotional for us and it has spurred us on to go even bigger and better for Leukaemia Care in 2024.

Since becoming involved in the charity, I have learned that my grandfather, who passed away the year before last at the age of 93, had been diagnosed with chronic lymphocytic leukaemia (CLL). It was something I had never known about him, but it has given me an even greater motivation and inspiration to take on these challenges."

Simon says...

"Barry and I live opposite one another and we got to know each other when Barry's wife was expecting their second child and my wife was expecting our first. We started running together, first doing Park Runs and then got involved in our local running

club. We've run the Virtual London Marathon three times together, but we are keen to do the real thing and have the roar of the crowd cheering us on.

This year, we swam Swim Serpentine for Leukaemia Care. It was important to us to do it for a charity so that there could be some benefit to others from our efforts.

After the race, we were standing with the Leukaemia Care team and a lady came up and said that she had leukaemia and that she was just so thankful for all the support she had received from the charity. A bit later another lady came over and said that her husband had leukaemia and had received a lot of help as well.

It was really overwhelming to feel that we were genuinely making a difference to people's lives. Realising how much good work Leukaemia Care does has motivated us to go a step further in 2024 and spurred us on to raise even more money.

Light training for the London Classics has already begun, but from the 1st January, our training will be full-on."

What are the London Classics?

The London Classics are the iconic sporting challenge, aiming to push sporting fanatics to their limits.

The classics comprise three of the world's most iconic mass participation events: The London Marathon, RideLondon 100 and Swim Serpentine.

More than 4,000 people have completed the classics, and we cannot wait to celebrate Barry and Simon who will soon join the fold in 2024!

Learn all about the classics over on their official website:
www.thelondonclassics.co.uk



PICTURE: BARRY (RIGHT) AND SIMON (LEFT) WITH OUR SENIOR CORPORATE AND EVENTS FUNDRAISING OFFICER YVONNE AFTER COMPLETING SWIM SERPENTINE IN AID OF LEUKAEMIA CARE

New year, new you?

"We have signed up for the London Marathon, Ride London and Swim Serpentine in 2024, as well as a half Ironman in France in June and we have applied for the Berlin Marathon too. We have set up a JustGiving page and everything we raise at these events will be donated to Leukaemia Care. We are setting ourselves a target of £5,000."

Fancy taking on something out of the ordinary? Want to be a part of a friendly and committed community of fundraisers, all with a big goal in mind? We would love to have you on the team!

But hurry... Places to many of our events are running low, so sign up before these opportunities sprint away.

Find out what you can get involved with [here](#).

Kes Grant: Turning seven

We celebrate our birthdays each year in many different ways. But, for many leukaemia, MDS or MPN patients who undergo a stem cell transplant, they will often celebrate their 'rebirthday'. This year, Kes celebrated her seventh rebirthday and reflected on her journey with us in this edition of Leukaemia Matters.

I recently celebrated my seventh rebirthday. I remember in my early 20s being told I had large red cells. The GP wondered if I was drinking too much, which I wasn't. I had iron deficiency anaemia (IDA) in 1994 with large cells too.

After two years without a clear picture, I was sent to a haematologist due to consistent low-grade anaemia. He did a biopsy and gave me a preliminary diagnosis of myelodysplastic syndromes (MDS). After another two years, I was sent to a Centre of Excellence who conclusively diagnosed me.

All those seven years ago, my little sister gave me the amazing gift of life in the form of her stem cells. It's not been an easy road to travel, and it still isn't. The fact I'm still here though, it's amazing.

I sometimes wonder why I'm here when so many wonderful people aren't as a result of their MDS or the treatment that follows. It makes me look at life differently. I just don't sweat the small stuff. I can smile at the beautiful sunset. Go out just to see the moon, watch the clouds and people walking by, enjoy the warmth of the sun and feel the gentle breeze on my face.

Before all this, even though I already had MDS, I used to take on life at breakneck speed. If I needed to do a 12 or 14-hour day at work, I did. I also had my church commitments at the weekend where I'd often have a sermon to write or service to take. I neglected my family at times because I felt an enormous responsibility to do all the things I'd said I'd do. I have a strong Protestant work ethic and it's not always a good thing.

When I had my transplant, I thought I'd give up a year of my life and I'd get back to work. That hasn't been the case.

Seven years on I'm still nowhere near being able to go to work, but I have found importance in letting all

those shoulds and coulds go. I live life more slowly. I have all the time in the world for my family.

When life's irritations come along I just think "Well, this is different", and I like different things. At the time of writing this, my home currently has no heating or water due to a leaking pipe. It's been this way for just over a week. I am wearing fleecelined snow trousers and four tops. We know what the problem is, we're just waiting to hear what the insurance company will do.

We have had friends and family who have offered to lend us a hand; some of the offers we have taken up. It's hard to stay too far away because we don't know when and who is coming to sort this out. It's further complicated by my partner starting jury service next week. Some people would (understandably) be really stressed about all this. I just think "sh*t happens" and it will get better. I also know it's a first-world problem. With what's going on in the world, I will never forget how truly blessed I am.

Not only does this mark my seventh rebirthday, but it also marks my commitment to live in peace with all that my body throws at me as well as strive for peace in the world. The thing about me is that I'm foolish enough to believe I can do that and make a difference.

Fancy joining me?

Want to know more about your diagnosis?

Alongside MDS UK, we have recently refreshed our MDS information booklet, to keep you up to date with everything you need to know about MDS, treatments and much more.

Get your free online or hard copy on our shop, which you can find [here](#).



Emma Blake Morsi: Behind the creation of Silence Provokes

How does meaningful art create stories? We spoke to Emma Blake Morsi, one of the talented artists behind Unicornfest as she describes her journey and the importance of storytelling within art.

Emmanuella Morsi, also known as Emma Blake Morsi is an award-winning Multi-Disciplinary Arts Producer and Non-Executive Director of Rising Arts Agency. She uses a fusion of different art mediums to spread awareness of topical issues and the stories of those who are impacted.

Emma was also the artist behind ‘Silence Provokes’; a beautifully crafted unicorn who was a part of our 61 Unicorn blessing over the summer. We spoke to Emma to talk all things inspiration, healthcare inequalities and her mission to make art as accessible as possible.

It’s great to talk to you Emma! Let’s go right to the start; how did you first delve into the world of art?

I have been in the industry for over a decade now. Growing up in Bristol means I have grown up in a creative hub of collaboration. I have been blessed to have been able to work and develop multi-sensory spaces that are neurodiverse friendly whilst tapping into inspirations such as nature.

A lot of the work I do now is as an art producer, delving into different aspects of art such as storytelling, illustration and design effects. There are so many practices and mediums we can use to tell a story, and coming up with different ways of creating has been a vessel for me to discuss issues on social or climate justice.

I am able to speak and work with a collective of artists who also use their respective practice to speak about these issues that I am so passionate about.

So, when the opportunity arose of being a part of Unicornfest I knew I wanted to be involved.

It certainly sounds like you have been keeping yourself busy. What inspiration was drawn on for the design of ‘Silence Provokes’?

I was feeling really inspired and I wanted to dig deeper into what the purpose of the Unicornfest trail was.

I researched Leukaemia Care and the work they do. I also knew the unicorns would be auctioned off which I loved. The whole project had this positive movement to it and it felt purposeful, and that was really special.

I personally and professionally know there are a variety of needs within these communities let alone the added complexity of navigating cancer within existing healthcare systems. So, I was really intrigued to explore more what insights existing research provided – from how diverse people were cared for, what disparities existed and what is being done about it.

I stumbled onto some interesting research, most notably by the British Journal of Cancer. The first of its kind in over 10 years, the 2021 research implied a variety of upsetting truths. Such as higher mortality rates despite low susceptibility rates in some cancers as a result of late diagnosis, mistreatment and bias in the healthcare system, and much more. But for true equity, these array of needs need to be considered from diagnosis through to treatment to truly improve quality of life.

So, this really began to spark this idea in my mind that we have people that are incredibly vulnerable, and their range of experiences should and need to be highlighted.

‘Silence Provokes’ is as much of a celebration of these cultures as it is to raise awareness of the differences that many minority ethnic people can

face in their care. I wanted to create a symbolic design that had an element of contrast - one half featured black and brown shapes which emphasised the intersectional groups, but on the flipside the other half would feature the vibrancy of colours, patterns and textures that are commonly associated with these marginalised communities.

I am proud that my unicorn celebrated the minority ethnic, queer, migrant and disabled by society communities; as a person of colour who comes from an intersectional background myself which has been rich in these vibrant patterns and textures, it is important to celebrate these factors, but I also wanted it to give people hope. I think 'Silence Provokes' was also a piece of art that made people stop and think; beneath the vibrancy was plenty of intentional research to raise awareness of these disparities. And that's really special.

'Silence Provokes' was homed at the Trinity Centre for the summer; a community arts centre and it was just the most perfect match. There was another project that was happening alongside Unicornfest that discussed climate injustice and they just worked great next to each other. I've always

loved that the Trinity Centre always stood for art, community and culture.

Thank you for sharing that with us - the art behind 'Silence Provokes' certainly has a powerful message. For anyone out there feeling inspired to pick up paintbrush or practise with textures, what would your best piece of advice be?

That's a great question! I think one of the biggest things for me is finding out what success means. Success is different for everyone. It's important to connect with a range of people that can offer you positive and constructive feedback. It is also a journey - one that is definitely worth embracing.

My journey is flowing in a way that aligns with my values; I spent time understanding what my values were and how I was going to portray that in my art. The creative industry is so subjective and it is emotional; you can easily lose focus of your objective and it can be exhausting. But, if you find those people you are inspired by and you reach out and connect with them, you are one step ahead.



How is Leukaemia Care tackling healthcare inequalities?

At Leukaemia Care, we believe that it is important to tackle the topic of healthcare inequalities head-on to ensure every person, no matter who they are, receives a fast diagnosis and the best care and support possible.

By working with those from minority ethnic backgrounds, we are working hard to ensure all voices are heard. We are thankful for patients from an ethnic minority background who share their story, which helps us continue raising awareness far and wide.

We are here to support you.



Join one of our virtual or in-person **support groups**.

Get one-to-one support from a **buddy**.

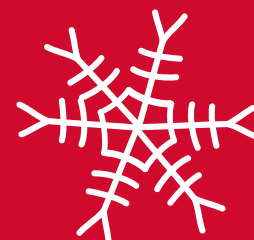
Speak to our **advocacy and welfare officers**.

Download or order **information booklets**.

Access our **counselling service**.



Write a **free will**.



For more information, advice and support:

Go to www.leukaemiacare.org.uk

Email support@leukaemiacare.org.uk

Call our nurse-led helpline **08088 010 444**

Or message us on WhatsApp **07500 068065**

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