CCLG The Children & Young People's Cancer Association

FREE

WINTER 2025 | ISSUE 109

contact

MAGAZINE

Blood and cancer

Why is blood important? What does it do? How might cancer affect it?

+ WHAT IS A STEM CELL TRANSPLANT?

+ WHAT IS CAR-T THERAPY?

Family Story

Phillipa Martin, whose son, Oscar, was diagnosed with leukaemia when he was three, tells us about the challenges of his treatment and the support her family received, and offers advice to other families navigating a childhood cancer diagnosis **Page 12**

KINDNESS, FRIENDSHIPS, COMMUNITY, AND A VERY SPECIAL HORSE

Charlotte Smith, whose daughter, Betsy, was diagnosed with leukaemia in 2023 aged five, explains what helped her family during Betsy's treatment, and how hope came from an unlikely source

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Winter 2025

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ON THE COVER

Contact

is a free, quarterly magazine for families of children and young people with cancer.

Contact aims to reduce the sense of isolation many families feel following a diagnosis of childhood or young people's cancer.

CCLG: The Children & Young People's Cancer Association brings together childhood and young people's cancer professionals to ensure all children and young people receive the best possible treatment and care. **Contact magazine was founded by The Lisa Thaxter Trust and CCLG and first published in 1999.**

Past issues of Contact: The wide variety of articles published during the year in Contact adds up to a valuable and informative reference archive. If you would like any back issues, please contact the Editor. Details of key articles in previous editions are listed on our website.

CCLG The Children & Young People's Cancer Association

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Your messages...

On Contact's last edition...

Lewis' story of resilience provides hope

"Truly inspiring, Lewis"

"What an inspiration."

Read Lewis' story **by scanning the QR code**

CCLG's information resources help support the whole family

"These documents help explain what's going on for everyone. From young children, to siblings, to parents and grandparents, they've helped us all."

CCLG's research webinars provide valuable insight for families and professionals alike

"Thanks for putting on these sessions, they are really valuable. I particularly like research-centred topics, where investigators can explain to a lay audience what work they are involved with."

"I work at a children's cancer charity and wanted to understand more about the topic. I have attended a number of these talks now and always find them well-run and interesting."

All CCLG research talks are available on YouTube: **www.youtube.com/@cclg-uk**

Hello!

The human body relies on blood to perform many functions for it to operate as it should do. But cancer and its treatments can affect the blood in many ways, especially when it involves blood cancers like leukaemia and lymphoma. These cancer types disrupt the normal production and function of blood cells, which are vital for immunity, oxygen transport and clotting.

Some treatments for cancer can also increase the risk of infection and blood clots and interfere with the body's ability to control bleeding. In this edition of Contact, we find out how doctors tackle this for children and young people affected in this way, and speak to healthcare professionals to offer insight into various procedures and therapies, both established and emerging, that are offering hope for children and young people with cancer.

Despite treatment and care continuing to improve, children and young people with cancer and their families still face a huge number of challenges and complications. That's why hearing the experiences of those who have walked this path before, and what helped them, is so important. We're grateful to all those who have shared their advice within these pages.

Sam

If you would like to **SHARE YOUR STORY** in Contact or have an idea for a theme for us to cover, please let us know. Email us at **editor@cclg.org.uk**

MEDICAL ADVISER

Prof. Bob Phillips

Candlelighters Chair of Supportive Care Research for Children and Young People with Cancer, University of York; Consultant Paediatric Oncologist at Leeds Children's Hospital; and CCLG member

Blood means so many things to us, both metaphorical and literal. Within a couple of weeks of a cancer diagnosis, most families know more about haemoglobin, neutrophils and platelets than 99% of the population.

This issue touches on most aspects of blood. Some of these you may know about and some you may not – what blood is made of, how it is made, why it gets affected by the various chemotherapy treatments, and what procedures (think transfusions, transplants etc.) there are to 'mend' the blood when it is damaged by cancer or the therapies used to treat it.

In terms of blood cancer, the science behind developing new treatments is becoming increasingly interesting and progressive. Take leukaemia, for example. Different scientists have made discoveries about the genetics within the leukaemia, the way the cells coat their outsides with proteins, carbohydrates and receptors, and what the cells need to continue to multiply, which have all opened opportunities to develop newer therapies and try to fine-tune how we use chemo.

To have a diagnosis of leukaemia, or any cancer, in yourself or your family, and go through the treatments we prescribe, is so much more than the science and the drugs, though. Living, growing and developing through the weeks, months and often years of chemo, is just the start. Beyond that is trying to move forward, through treatment and after it, sometimes carrying its effects in your mind and body, as you go through life.

So, there's an enormous need to coordinate our efforts in understanding and refining our approaches to our wider care, not just how we treat the malignancy. It's not just about genetics and blood tests, but other ways of thinking which we need to develop, as part of the complete care package, both during and after treatment.

Thankfully, this is happening, and between us all, we'll keep working hard to improve this.

NEWS IN BRIEF

New discovery links circular DNA to childhood leukaemia relapse

Scientists have found that circular pieces of DNA, by-products of antibody gene formation, can persist inside leukaemia cells and make relapse more likely. This breakthrough could help doctors spot children at higher risk of relapse much earlier, so they can receive the right treatment sooner.

(Source: Nature)

A risk-based approach for follow-up after childhood cancer

Research shows that survivors of childhood cancer with certain genetic mutations are over four times more likely to develop another cancer than survivors without mutations. This finding suggests that genetic testing should be considered in long-term care to better tailor follow-up and treatment.

(Source: Journal of Clinical Oncology)

Lymphoma could be prematurely ageing immune system cells

Lab research shows that B-cell lymphoma can cause children's cancer-fighting T-cells to take on 'aged' features. This weakens their ability to fight cancer and leaves lasting changes to the immune system. Understanding and addressing how these changes persist after treatment could help improve survivors' long-term health.

(Source: Cancer Cell)

Timing matters for brain tumour treatment

Research has shown that paediatric high-grade glioma cells follow daily cycles of gene activity, which affect how well chemotherapy works. Aligning treatment with these rhythms could improve the effectiveness of chemotherapy drugs like temozolomide.

(Source: Nature)

Immune cells found in brain tumours could boost tumour survival

A new study shows that immune cells in children's low grade gliomas may help the cancer evade the immune system, allowing it to grow back after treatment. Understanding more about these immune cells could lead to more effective treatments and better ways to predict which tumours will return.

(Source: The Brain Tumour Charity)

Kelly and Evie

The importance of platelet transfusions in childhood cancer

***Kelly Herriott's** daughter, Evie, was diagnosed with neuroblastoma in 2020 when she was 21 months old. Here, Kelly explains how Evie's treatment affected her blood, offers advice to others facing a childhood cancer diagnosis, and tells us what life looks like for their family now.*

Before Evie's diagnosis, I had no knowledge of neuroblastoma or blood platelets, and how important platelets are during cancer treatment. Platelets are crucial for everybody to help with clotting and to stop bleeding. If these platelets are low and a person doesn't have enough of them, it can then become life threatening.

The eight rounds of chemotherapy that Evie received had a huge impact on her platelet levels. The drugs she received affected her bone marrow, which is the site of platelet production. Evie had regular blood checks to check her platelet levels, and we were told to look for vital signs of low platelets, which included bleeding gums, nosebleeds, bruising easily and a petechiae rash (tiny red/purple spots which appear in a cluster).

It turned out that for every round of chemotherapy that Evie received, she required a platelet transfusion. One cycle of chemotherapy took a huge toll on her platelets, so she needed two transfusions to get her levels up to where they needed to be.

We managed to catch Evie's neuroblastoma quite early on, before she displayed any symptoms. Unfortunately, most other cases that we've seen on our journey have been diagnosed as high-risk stage 4. Evie's diagnosis was stage T2, classed as intermediate risk. The children we've seen going through the higher-dose chemotherapy have needed multiple platelet transfusions for every round of chemotherapy they've received. These are so vital for anybody going through cancer treatment, as well as blood transfusions. In total, Evie needed eight blood transfusions and nine platelet transfusions. She then went on to have 12 rounds of radiotherapy and six months of maintenance chemotherapy.

Evie's treatment worked exceptionally well and she was able to ring the end-of-treatment bell on her third birthday in December 2021.

Evie ringing the end-of-treatment bell

Other challenges and what helped us

Evie was diagnosed in September 2020 in the middle of the COVID-19 pandemic, which was another challenge we had to face. This meant the hospitals were very strict and, on most occasions, they had the one parent rule in place. Our son, Harry, was 10 years old at the time, so we had to make sure he was doing okay and that Evie's diagnosis didn't affect him too much.

We were open and honest with him from the beginning of Evie's diagnosis and the Royal Marsden Hospital was amazing at providing children's books so we could explain to him what Evie was going through in a child-friendly manner. We had a lot of support from family members, and my parents were able to look after Harry when COVID rules allowed.

We're so grateful for all the amazing care Evie received during her treatment. I'd say to anyone currently going through this to trust the healthcare professionals, but also don't be afraid to ask questions and trust your instincts as a parent as you know your child better than anyone.

What life looks like now

Evie is now a confident, loving six-year-old. She attends school and is doing really well. She has regular check-ups and has recently had a routine six-month scan at the Marsden. She also has regular heart echo tests to check the effects of the chemotherapy, which so far have all come back okay. Luckily, Evie doesn't remember too much about her treatment and is thriving.

She's now enjoying swimming again, something she couldn't do during her treatment due to having her Hickman line in place. We now take great pleasure in watching her participate in her swimming lessons. We never take any day for granted, and we look forward to seeing what Evie will achieve in the future.

▶ Evie during treatment

COVER STORY

A story of kindness, friendships, community, and a very special horse

***Charlotte Smith's** daughter, Betsy, was diagnosed with leukaemia in 2023. Here, Charlotte explains what helped her and her family during Betsy's treatment, the support she received, and how hope came from an unlikely source.*

Back in March 2023, Betsy had been poorly for around six weeks. She first became unwell when she had an ear infection, which she never really bounced back from. She kept spiking temperatures and became fatigued and not wanting to play with her sister after school. Instead, she'd just fall asleep on the sofa. It was such a change from her normal, fun and energetic personality.

Symptoms then became more concerning when she began getting persistent pains in her stomach, ankle and arms. It was at this point she was taken to a GP, and we visited an A&E department where we were told it was likely viral. However, for me, panic had already kicked in. As a mother, to see your child suffering and not having any answers or a way to make it better was nothing short of torture. The final symptom she showed was sweating at night. I'd have to change the bedclothes and dry her down with a towel. It was at this point, after another desperate and panicked visit to the GP was made, that Betsy was eventually sent for blood tests, and I felt listened to.

Unfortunately, the results of those blood tests would change our lives for ever. I remember being on my own with Betsy at our local hospital after they had phoned for us to come in urgently. Her dad, Christian, had gone to Cheltenham Festival for the day. He's a racehorse trainer, so that day was a very important day in the calendar for him, and in truth I think he thought I'd been worrying over nothing.

The doctor huddled into Betsy's bay and said: "We believe Betsy has leukaemia." I stood frozen to the spot, and everything that was said after that seemed to be in slow motion. I remember looking back at her as he was speaking. She was curled up on the bed stroking the hair of the doll I'd just bought her, completely oblivious to the enormity of the words being spoken. My heart shattered into a million pieces in that moment and the desperation and fear I felt is something words could never describe.

We were quickly transferred to Noah's Ark Children's Hospital in Cardiff where we were met by a team of the most incredible doctors, nurses and play specialists. It was then that Betsy was confirmed to have B-cell acute lymphoblastic leukaemia, and we knew that life was going to look very different from that point on.

The importance of mutual support

On our first day on the ward, another little boy a couple of years younger than Betsy had been given the same diagnosis. They had their ports put in and started treatment at the same time. Every chemo and lumbar puncture in those first six weeks, which are so difficult, were together. Having another family to go through this with, and to support each other, made such a difference to our lives.

During this time another little girl was diagnosed with acute lymphoblastic leukaemia on the ward, and she turned out to be in the same school as Betsy. They hit it off straight away and are now the best of friends. They helped each other through procedures like having their ports accessed and held each other's hands every week when having bloods taken. On the occasions where they couldn't go to school and were isolating, we'd go over to each other's houses to keep each other company.

We've formed a lot of strong friendships on the ward along the way. We have a gang of us now, who talk daily and support each other during the difficult days. I'm so grateful to them and have no doubt we'll all be friends for life.

Finding a ray of light

Despite our newly formed friendships, those initial few weeks were difficult for Betsy. The steroids would make her angry, her hair had started to thin, her legs would ache and become weak, and she felt so poorly and sad that she couldn't go to school or see her family. During those difficult weeks we managed to see a bit of light that happened to be in the shape of a horse.

One day, Betsy was having a particularly difficult day, and her daddy had gone to Scotland to take one of her favourite horses, 'Kitty's Light', to race in the Scottish Grand National. This was our business, and we had so many people relying on us, we were clinging on by a thread to keep this going. I was able to go on sick leave as I worked for the NHS, but Christian had 10 members of staff, horse owners, and 50 horses to look after, so for him, that wasn't an option. I'm ashamed to say I wasn't very interested in watching it, as I wasn't particularly interested in anything at that point. However, we turned on ITV Racing and, to our amazement, this little warrior of a horse won against all the odds. I can't describe the lift in mood it gave us. It gave us that little bit of hope that good things can happen to us and gave us the motivation to keep pushing on. That special horse has continued to give us so much joy and special memories all through Betsy's treatment.

Betsy and sister, Tilly, before the Grand National

How kindness and community helped us

> "The doctor huddled into Betsy's bay and said: "We believe Betsy has leukaemia." I stood frozen to the spot, and everything that was said after that seemed to be in slow motion."

During the ITV broadcast, it was mentioned that Betsy had been diagnosed with leukaemia, and from there, messages of love and support came flooding in. These messages helped me in more ways than you can imagine. Friends and family rallied around us, food was made for us, care packages were delivered, and gifts were given to Betsy and her sister, Tilly. A huge amount of fundraising was also done in Betsy's name by so many amazing people. So far, over £150,000 has been raised for charities such as LATCH, The Little Princess Trust, Noah's Ark, and CCLG. These charity events gave us something to look forward to, and included a park run, rounders tournaments, sponsored races at Chepstow races, cake sales, marathons and half marathons, and hair cutting. You name it, people did it. Everyone who helped support us or organise these fundraisers are so special to us, and we'll never forget their kindness.

▶ Betsy during treatment

Betsy, who's now eight, has finished treatment and rang the bell in July. She was surrounded by her little friends from Rainbow Ward who are still having treatment. She was the first of the gang to ring the bell, and it felt bittersweet seeing her finish while her friends still have so much treatment left.

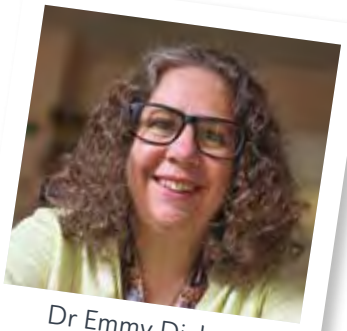
Since Betsy's diagnosis, our lives have been changed beyond measure. We'll never take anything for granted again. Life is for living and we're going to live it the best way we can, together. One thing is for sure – we wouldn't have got through the past two years without the friendships we made on the ward, the kindness shown to us by so many people, and the hope given to us by a special little horse.

▶ Kitty's Light

back to basics

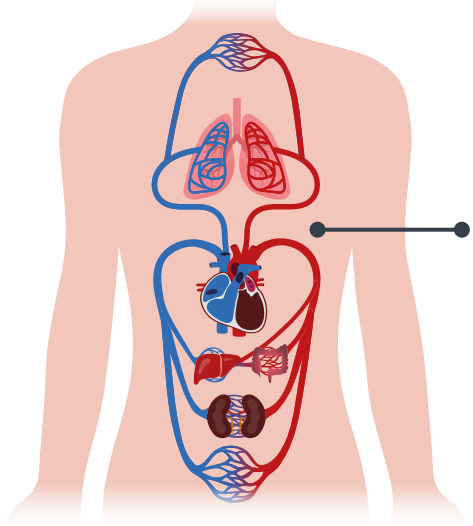
What is blood?

Blood is vital for the body to function properly. ***Dr Emmy Dickens****, a consultant paediatric haematologist at Addenbrookes Hospital, explains what blood is and why it's important.*



Dr Emmy Dickens

Blood is a vital fluid that circulates throughout the body and keeps you alive. It transports oxygen from your lungs to every part of your body and brings nutrients to your cells so they can work properly. Blood also helps remove waste products, fights infections, and helps heal cuts. Whole blood is made up of about 55% plasma (a straw-coloured liquid containing salts, proteins, sugars and fats suspended in water) and 45% blood cells. It travels through an extensive network of blood vessels, including arteries and veins, which carry it to and from all parts of the body. At the smallest level, blood flows through capillaries – tiny, thin-walled vessels where the exchange of oxygen, nutrients, and wastes occurs between the blood and surrounding tissues. Through this continuous circulating movement, blood plays an essential role in supporting every cell and maintaining overall health.

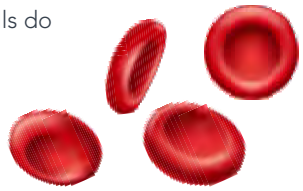


Blood circulation through the body

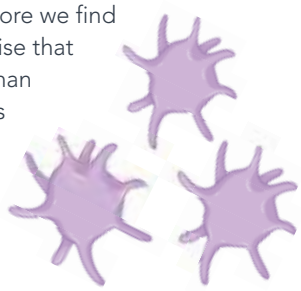
Types of blood cells

There are three main types of blood cells and they each perform a specific role to help keep you healthy, protected and functioning every day. They also look quite different under a microscope. All blood cells are made in your bone marrow which is the spongy bit in the middle of your bones. If we need to know if your body has a problem in making blood cells, we can take samples of your bone marrow and examine them under the microscope.

- **Red blood cells (called erythrocytes)**
  Most of the cells in your blood are red blood cells - they look like round discs that are fatter around the edge than in the middle. They don't have a nucleus like most other body cells, but they use that extra space to pack in loads of haemoglobin molecules, giving them their red colour. Haemoglobin is an iron-rich protein that can bind to oxygen when there's lots of it around (e.g. in the lungs) and let go of it when there's not much of it in the environment (like in the tissues). Red blood cells do the important job of transporting oxygen to other cells all over the body to allow them to carry out their own important jobs.

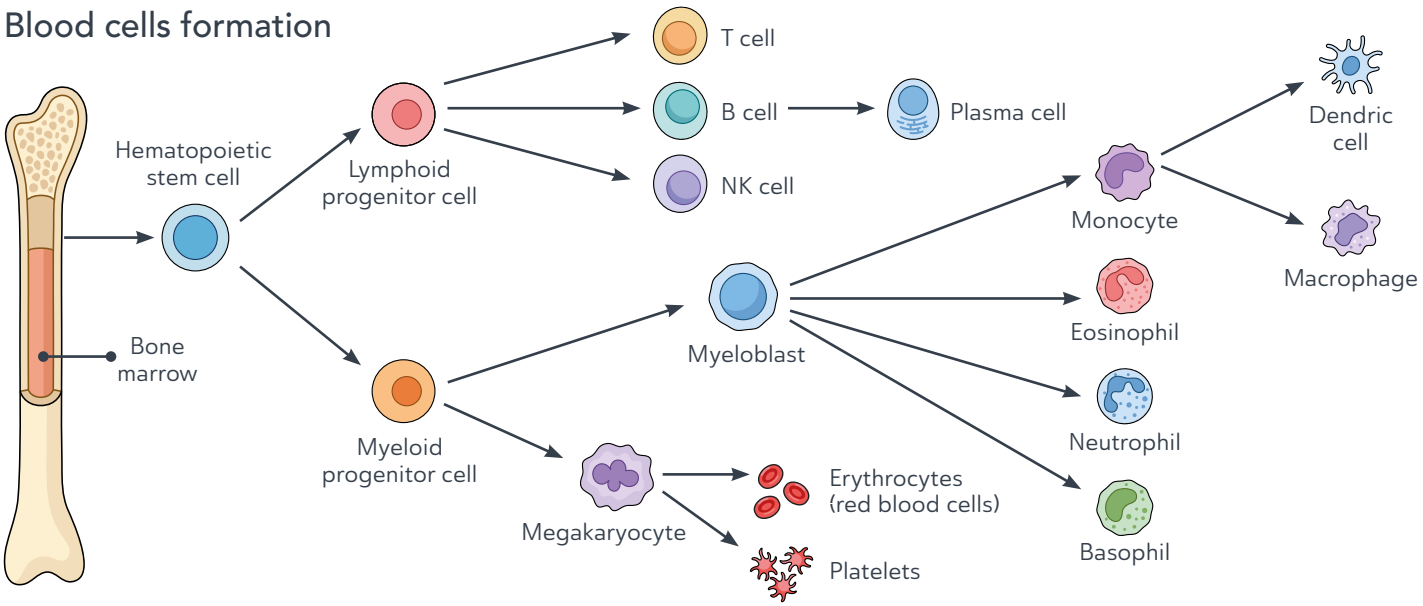


- **Platelets (called thrombocytes)**
  Platelets are small purplish cells that help your blood to clot, which means they stop you from bleeding too much when you get a cut. We used to think platelets only stopped bleeding, but the more we find out about them, the more we realise that they're much more complicated than that. They contain many chemicals that have no known role in blood clotting, they are part of the inflammatory response, and they can bind directly to bacteria.



- **White blood cells (called leukocytes)**
  White blood cells are the body's defenders; they help fight infections by attacking germs like bacteria. There are several different types of white blood cell:
  - **Granulocytes** are a group of white blood cells that include neutrophils, eosinophils and basophils. They're quick to fight infection, often by swallowing germs and destroying them. Neutrophils are especially important as they can react very quickly as first responders and are very good at stopping us from becoming unwell when we have bacterial infections.
  - **Lymphocytes (B cells and T cells)** are part of our adaptive immune system, which provides a more sophisticated response to infection. B cells produce antibodies and T cells have receptors on the cell surface that can recognise proteins from germs that might cause us harm. The lymphocyte response can be tailored to specific infections, and they can remember infections we've been exposed to in the past. Lymphocytes are the reason most of us will only get chicken pox once!

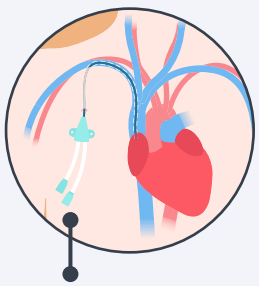
Blood cells formation



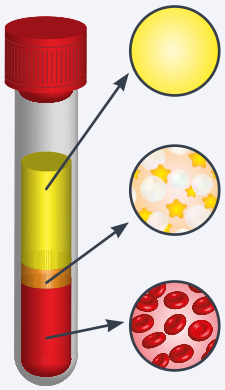
Taking blood samples

When we take blood, we use different sample tubes depending on whether the test is done on whole blood, serum or plasma. Sometimes the blood samples need to go to different laboratories too, so we often need several different sample tubes.

By measuring different salts, proteins, enzymes, hormones, antibodies, fats, glucose and other elements in the blood stream, we can tell how well different organs, like the kidneys and liver, are working. We can tell whether a body has enough nourishment, we can measure inflammation and see how well the body is responding to challenges like infection. Some blood tests can tell us about damage to organs like the heart, liver or pancreas and others can tell us whether hormone systems or blood clotting are working as they should. We can look at numbers of blood cells, measure drug levels and even extract DNA to look at an individual's genetic make-up.



Central line on the chest for taking blood tests



How chemotherapy may affect the blood

Your bone marrow is constantly working to produce new healthy blood cells. Red blood cells survive for around three or four months in the bloodstream once they've left the bone marrow, but platelets only last for seven to 10 days and neutrophils for less than 24 hours. As many chemotherapy drugs interfere with cells reproducing, they can have a particularly powerful impact on bone marrow, which has to produce many millions of cells every day to maintain a normal blood count.

Anaemia is a low level of haemoglobin in the blood, reducing the amount of oxygen that can be delivered to the tissues. This can make people feel washed out, tired, breathless, or dizzy. If the haemoglobin is below a certain threshold, or someone's having symptoms of anaemia, a red blood cell transfusion can be used to top up the haemoglobin level.

Many patients receiving chemotherapy will have a low platelet count at some time during their treatment. We call this 'thrombocytopenia', and it can lead to easy bruising or bleeding (like nosebleeds, gum bleeding or skin rashes). Sometimes this can be improved with medicines, but if there's significant bleeding, a platelet transfusion can be given.

A low neutrophil count is also common in children or young people who've had chemotherapy treatment. This is called 'neutropenia' and leaves people vulnerable to severe infection, potentially leading to sepsis. Sometimes it's possible to shorten the period of neutropenia by using a growth factor called G-CSF, but this isn't suitable for use in all conditions. Granulocyte transfusions are possible, but they're more risky than other transfusions and aren't good at preventing infections, so they're reserved for life-threatening infections. The most effective treatment for bacterial infections is the prompt use of powerful antibiotics, which is why patients on chemotherapy treatment are asked to come straight to hospital if they are feeling feverish, shivery, unwell, have a raised or very low temperature, or show any other signs of infection.

Craig Baillie

What is a stem cell transplant?

***Craig Baillie** is a stem cell transplant clinical nurse specialist at Royal Hospital for Children in Glasgow. Here, he explains what a stem cell transplant is, the different types, and the process of receiving one.*

Stem cells are the blood making factories found within the bone marrow (contained in the soft cavities inside the bones). Stem cell transplants are used in the treatment of some cancers. Sometimes, they act as a rescue where high doses of chemotherapy have damaged the body's own ability to generate blood-making cells. In other circumstances, they can help to trigger an immune response against cancer cells.

What are the types of stem cell transplants?

There are two types of transplants: autologous (using a patient's own cells) and allogeneic (using donor cells). In autologous transplants, the cells are harvested from the patient's own blood. In allogenic transplants, donors' cells are taken from either bone marrow, umbilical cord blood, or circulating blood.

Why may a child or young person need one?

Stem cell transplants are used either as part of the treatment pathway depending on cancer type, where the patient has had a poor response to initial treatments, or in most cases, where there has been a relapse. Transplants are also used as the treatment where there are certain genetic markers that indicate this is appropriate.

Who can have one?

Having a stem cell transplant is influenced by a wide range of factors. There are some types of cancer where transplant will definitely be part of the treatment plan, and there are others where transplant is required because of a poor response to initial treatment or relapse. In the cases of allogenic transplants, there must be suitable donor options.

How are donors selected (allogenic only)?

We're looking for a match based on human leukocyte antigens (HLA), a protein marker in our immune system. The best matches are siblings if available, followed by HLA-matched unrelated donors.

What are the different sources?

- **Bone marrow:** Where cells are taken directly from the bone marrow of the donor. This is done as a surgical procedure.
- **Cord blood:** Where a match has been found to donor cells in a cord blood bank where cells were taken at birth from an umbilical cord.
- **Peripheral blood stem cells:** The donor is given a drug to stimulate high volume of blood making cells to enter the peripheral blood. The blood is then harvested.

What does the process look like?

Step 1 – Baseline investigations: We check and record all organ functions and infection markers. These tests give us a good understanding of how everything is working 'pre-transplant' so that if anything changes, we can quickly detect and treat it.

Step 2 – Conditioning: We admit the child or young person to hospital and start isolation protocols. This is because they'll be vulnerable to infection, and we treat in protected isolation. We need to make room in the bone marrow for the new cells, and this is done using chemotherapy and (or) radiation. This process effectively breaks down the patient's own immune system – hence the need for isolation protocols. The exact conditioning process will be tailored to the patient with factors like age and cancer considered. Patients can expect to be prescribed many medications at this stage.

Step 3 – Stem cell infusion: We infuse the stem cells around seven to 10 days after the conditioning treatment has started. The cells are infused through the central line, and the process is typically completed within a couple of hours.

Step 4 – Engraftment: This is when we can see that the new cells are beginning to function. This means the immune system is beginning to work and the blood making cells are active. We expect this will happen between two- and four-weeks post infusion. After this, it's normal for isolation protocols to be relaxed.

Step 5 – Post-transplant: By now, the patient has a new – but fragile – immune system. Patients should expect to be taking medications for a long period of time and will have frequent visits to the hospital. They won't be able to get straight back to their old lives – there'll be necessary restrictions and precautions until the new cells are at fully functional levels.

How our experiences are driving us to help other families

***Laura Sheppard's** son, Max, was seven years old when diagnosed with acute lymphoblastic leukaemia (ALL) in May 2023. Here, she tells us about his treatment, the support they received during it, and why her family now wants to make a difference to others.*

▶ Laura, Max and Ronnie

Before Max's diagnosis, he played football and rugby every week. Everything he did revolved around sport. He was normally full of energy, but for a couple of months, he hadn't been himself. He was extremely lethargic. He'd walk upstairs and fall asleep on the way. He'd had multiple sickness bugs as well and he kept picking up every bug going. And then he started coming up in unexplained bruises.

Max during treatment

One evening, after the bruises appeared, I took Max to the hospital on the advice of 111, where after suffering a seizure and having a really high temperature, he was diagnosed with sepsis. Max spent a week in hospital, during which time his bone marrow became suppressed. Over the coming months, he was carefully monitored with blood tests to check his bone marrow was repairing itself as it should have been.

Doctors had briefly mentioned the possibility of Max having leukaemia, but his blood tests weren't showing conclusive evidence. We were going for weekly bloods, and we were told it was doing what it needs to be doing, but they'd keep monitoring him.

He went back to school. He had his birthday party. And then on the fourth week, we had his bloods done in the afternoon, went home, and then we got a phone call saying we needed to go to A&E. We got him out of bed, went in, and were taken to a side room and told he had leukaemia. It was a massive shock.

Max's treatment

Max's treatment began quickly, but despite nine months of chemotherapy, autoimmune therapy, transfusions and various other procedures, his cancer was still present. This meant he would need a bone marrow transplant. We were told that without one, his chance of survival was just 10%.

Sadly, none of us in the family were matches, but in time, an anonymous full match was found on the register. We were admitted to a hospital, miles from home for over five months while Max underwent pre-transplant treatment. This included full-body radiation twice a day for several days before he could receive his 'magic cells'.

This was a really difficult time for us as a family, both because of the intensity of the treatment and because it meant Max and I had to be away from home, away from his dad, Dave, and his older brother, Ronnie. It was complete isolation. It was really tough.

Support from CCLG

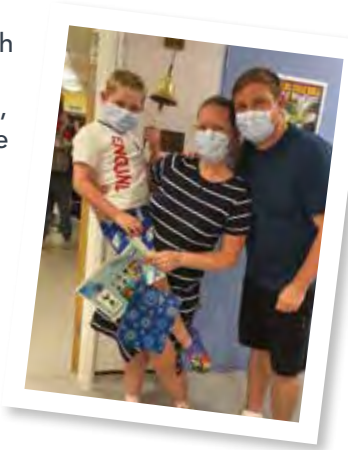
During Max's treatment, we were supported by CCLG's information resources, which especially helped in those early days and weeks after his diagnosis. CCLG's information was one of the first leaflets we were given. When Max got diagnosed, the doctors told us not to google anything. CCLG's leaflets explained exactly what each individual treatment is, what leukaemia is and what his type of leukaemia is. So, we've always gone to CCLG's website, rather than googling and it's been a real help.

Max's treatment was a bumpy ride. Nothing was easy. But support from charities like CCLG helped to make things a little easier.

What life looks like now

Max is now nine and finished treatment in May 2024. Though he's still being closely monitored, he's doing really well. He's at sports club now, still football-mad, and back to running around. He's not as fit as he used to be, or as he'd like to be. But he's getting there.

As a family, we're now dedicated to raising funds for research into childhood cancer and awareness of it and its impact. As a parent, I want to help ensure other children who receive a cancer diagnosis stand the best chance of recovery.



▶ Max with Laura and dad, Dave, ringing the end-of-treatment bell

Phillipa and Oscar with dad, James, and sister, Imogen

Navigating the challenges and impact of our son's leukaemia journey

***Phillipa Martin's** son, Oscar, was diagnosed with acute lymphoblastic leukaemia when he was three years old in 2022. Here, Phillipa tells us about the challenges of treatment and the support her family received, and offers advice to other families navigating a childhood cancer diagnosis.*

The day your child is diagnosed with cancer is a day that shatters your world. The signs were subtle, yet terrifyingly clear in retrospect. Just a few days before his official diagnosis, we took him to the GP with a temperature and earache. We were told he had a virus, but a parent's instinct is a powerful thing. The next day, I noticed a very small, strange rash on his eyelids. When I pressed on it, it didn't blanch. We knew something was wrong.

We rushed back to the GP, where a nurse practitioner, thankfully, shared our concern. She called in a specialist GP who immediately wrote a letter for us to go to hospital. We were told not to worry, but our hearts were already pounding. We arrived at the hospital, and after a long wait, Oscar had a blood test. A play worker then came to sit with Oscar and we were escorted into a room with tissues on the table. Our hearts sank as we were told they suspected leukaemia.

Our 'new normal'

Within hours, we were transferred to Sheffield Children's Hospital and admitted to the cancer ward. It was Jubilee weekend, a time for celebration, but for us, it was a time of unimaginable grief and fear. Oscar was quickly fitted with a portacath, and his treatment began with chemotherapy. We were given a treatment plan which included chemotherapy drugs and steroids.

Oscar's treatment lasted for more than two years. Throughout this time, we had to find a way to navigate this new reality, not just for Oscar, but for our whole family. We quickly learned to work to the strengths of our relationship. I couldn't cope with being at home when our baby was so poorly, so I'd stay at the hospital during the night. My husband and Oscar's dad, James, couldn't deal with the constant lack of sleep, so he'd be at home. He'd then come to the hospital to share the 'day jobs', allowing me to have walks in the park, take a breath of fresh air, or just keep me company on those lonely days. This approach also helped with continuity for our three other children, who were also sharing the burden of the unknown every day.

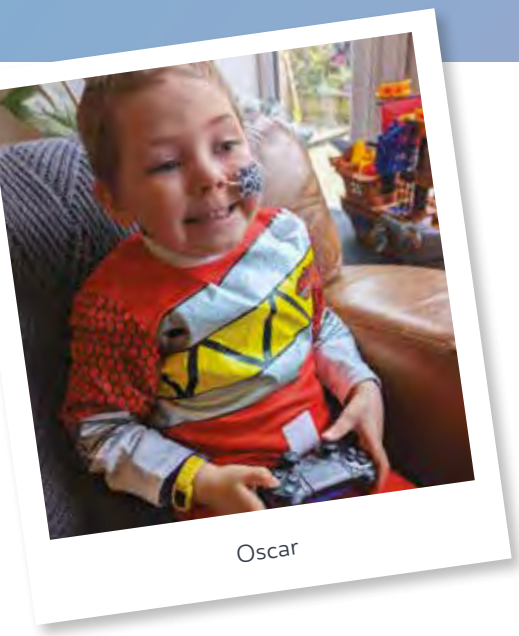
> "The hospital staff were outstanding, offering us support, a shoulder to cry on, and never judging the battles we were going through."

From the very beginning, we agreed to Oscar being placed on a clinical trial. We wanted to ensure he was getting the most cutting-edge treatments available, and we also wanted to help other families by contributing to research. But this had its own challenges. Partway through the treatment, we were faced with a decision that felt impossible. We were asked to choose between two paths which had different risks and benefits attached. I spent many hours crying over this decision. The hospital staff were outstanding, offering us support, a shoulder to cry on, and never judging the battles we were going through.

The challenges and impact of treatment

The steroids were particularly tough. They caused huge changes in Oscar's mood, appetite and mobility. There were days we couldn't leave the kitchen because he was constantly hungry. Then, just as suddenly, the steroids would stop, and he'd lose his appetite and start getting sick every day. We made the difficult decision to have a nasogastric tube placed to help with medication, hydration and nutrition. This made a world of difference, saving us from constant battles just to get him to eat or take his medication.

Oscar was incredibly brave and compliant through countless blood tests, scans and procedures. This included numerous theatre trips. He had to have bone marrow taken for testing and chemotherapy injected directly into his spine. No matter how many times we went, we never got used to seeing our child be put to sleep. It was heart-wrenching. He often woke up distressed and very sickly, but the staff were amazing in ensuring he was given the best care, from holding his hand until he drifted off, to comforting him when he woke up.



Oscar

The anaphylactic episode he had from one of his chemotherapy drugs was a terrifying setback. The ambulance came to our house and took him to our local hospital, where he was treated and admitted. This meant a complete change in his treatment plan, with a different chemo drug administered every other day for four weeks.

We also made the difficult decision to shave Oscar's head before his hair started to fall out. This was a moment of taking some control back in a situation where we felt powerless. A small highlight during this time was hydrotherapy. It was the only time we saw Oscar truly happy and mobile, free from the pain and stiffness that the steroids had caused.

The biggest challenge, however, came during the maintenance phase of treatment. We'd been told it would be easier with fewer hospital trips, but Oscar became very ill with recurring infections. Seeing him on oxygen, fighting for his life, was harrowing. Eventually, the hospital reduced his chemo levels, and things slowly became more manageable.

The power of support

This journey wasn't one we walked alone. We received immense support from various organisations. Young Lives vs Cancer helped us with practical things, like applying for Disability Living Allowance and a blue badge, which made hospital trips with Oscar's decreased mobility much easier. PACT, a charity for parents of children with cancer, provided comfort with food and presents. The hospital chaplains and staff were amazing, and the POONS (paediatric oncology outreach nursing specialists) were always at the end of the phone, ready to help.

But the biggest support came from the other families on the cancer ward. We formed a unit, sharing our experiences and understanding each other in a way no one else could. We were a community built on shared struggle and hope.

Moving forward

As the end of treatment approached, I began to struggle with my own mental health. I was terrified of being left without the constant support of the hospital, of having a vulnerable child and feeling alone. Psychology services were a huge help for both Oscar and me during this time. Oscar still struggles with anxiety and separation issues, but he's becoming more confident. This year, we were finally able to enjoy our first family holiday, a truly cherished moment.

Oscar is now seven and is on six-monthly check-ups, with blood tests and a chance to talk to the doctors. He still has ongoing leg pains, for which we're supported by physiotherapy. This journey affected our whole family, including his three older siblings, who also received support.

Our journey has been a testament to resilience, hope and the incredible power of love. We're so proud of how far Oscar has come, and grateful for every new day we have with our brave, beautiful boy.

▲ Oscar with his dad, James

▶ Oscar with his beads of courage

Our advice to other parents

- **It's okay not to be okay.** Treatment is hard, and you'll have tough days. But don't suffer in silence. The hospital staff and other parents are there to support you
- **The steroids are tough, but it doesn't last for ever.** The side effects are brutal, but they're temporary
- **Make the hospital feel like home.** Bring things that make you and your child feel comfortable
- **When people offer to help, take it.** You can't do this alone
- **Be kind to yourself.** Do whatever makes your life easier during this impossible time
- **Be honest with your child.** Let them be part of their treatment. Don't make promises you can't keep. It's okay to tell them that something will hurt, but it's making them better
- **Trust your instincts.** If something feels wrong, get it checked out

“Take each day as it comes”

***Samantha Hall's** son, Jackson, was diagnosed with T-cell acute lymphoblastic leukaemia aged two in 2020. She describes the impact this had, what life looks like now, and offers advice to others navigating treatment.*

Sam, with Jackson, his dad, Shaun, and sister, Ava

On 2 February 2020, we took Jackson to our local A&E, as he had what I now know is a petechiae rash on his stomach and back. Jackson's dad, Shaun, and I knew to get any rashes checked out as we'd already gone through a scary experience when our niece had meningitis. As Jackson's rash wasn't going away with the tumbler test, we were very concerned. However, we never imagined it to be leukaemia.

For me, being told my son had cancer felt like the world had stopped. Life changed for ever. It's surreal to think back and realise how quickly things happened. One day you're sitting on the sofa watching a film with your kids. The next, you're in hospital signing consent forms for potentially life-altering medication to treat a life-threatening condition for your toddler.

Jackson's treatment hugely impacted family life, especially as it happened at the height of a pandemic. At the time, Jackson's sister, Ava, was six. We were almost always separated, and Shaun and I would take it in turns to stay with Jackson. In the first year of treatment, we were admitted countless times. With every temperature that hit 38°C, we had to take Jackson into hospital for a 48-hour minimum stay, which is standard protocol.

“Jackson's treatment hugely impacted family life, especially as it happened at the height of a pandemic.”

During the hardest parts of Jackson's treatment, it helped having such an amazing team behind us. The nurses at St Georges were like family and I can't thank them enough for how they got us through such difficult times. The Royal Marsden also provided Jackson's sister with a course of art therapy, as she struggled at the beginning and we found it helped her a lot.

Both hospitals gave us great support and information whenever we needed it. We've also worked with some amazing charities, such as Momentum Children's Charity, Rays of Sunshine and Lennox Children's Charity Fund. In May this year, Jackson completed the five-mile Banham Marsden March, raising money for The Royal Marsden.

▶ Jackson in remission

Life after treatment

Jackson, now eight, finished treatment in April 2023 and seeing him ring the bell will always be one of my proudest moments. He's now five years in remission and we celebrate each milestone he encounters. Because of the age he was diagnosed, Jackson missed a lot of school, only starting properly in year 2. However, he's been thriving ever since.

Since treatment ended, we've made some great memories doing things we couldn't do before. And our family has also grown. Ava and Jackson now have a baby brother called Louie, born last year. We call him our 'puzzle piece', and Jackson is besotted with him.

Since Jackson's diagnosis, I've maintained a page about his cancer on Instagram. What started as a way to keep family and friends informed of his treatment has now become a place where I can help others. We've met so many families in the cancer community. It's something you never want to be a part of, but we've made great friendships that will last a lifetime.

My advice to others

I always say to newly-diagnosed families to just take each day as it comes. There will be good days to be enjoyed and taken in, and there will be bad days, where you need to ride the storm. I'd also say it's important to not be afraid to seek advice or ask questions. No question is a silly one, especially when your world has just been turned upside down and you're trying to navigate a new way of life. We also found writing a daily diary helped, especially with keeping track of medication.

Although it feels like things won't get better, there's always light at the end of the tunnel. I can't say the worry ever leaves you, but it certainly gets easier as time passes.

▶ Jackson during treatment

@JacksonsJourney_2020

A parent's view...

Why lived experience is vital to developing research

Kate Willis' son, Sebby, was two years old when he was diagnosed with acute lymphoblastic leukaemia in 2017. Kate tells us about Sebby's treatment, how this influenced her to help shape research, and the importance of patient and parent voices in research discussions.

Kate and Sebby

Before his diagnosis, Sebby had been unwell for a few weeks with viruses and sick bugs, but we'd assumed it was because he'd just started nursery. Then, he started to get nose bleeds, night sweats and eventually spots behind the knee and under the arms. We went to the GP who sent us straight to our local hospital for a blood test and we were told he had leukaemia soon after. Two days later, he was transferred to the Royal Marsden, where his diagnosis was confirmed.

Sebby during treatment

He had all sorts of chemotherapy, and a lumbar puncture under general anaesthetic every 12 weeks to inject chemotherapy into his spinal fluid. The community nurses visited him at home or school once or twice a week to do a blood test. He had a portacath fitted in his chest so drugs could be administered and blood taken easily.

Sebby was immunosuppressed for the whole three-and-a-half-years of treatment, so was vulnerable to infections. If he spiked a temperature of 38°C, we had to get to hospital within an hour, and he was treated with intravenous antibiotics. He had a course of steroids for one week out of every month and took oral antibiotics throughout his treatment.

The impact of treatment on children and their families is huge. Life changed for all of us when Sebby was diagnosed. It's particularly hard for siblings, who are often left behind. Sebby's older brother, Xander, was four when Sebby was diagnosed. He was old enough to know that something serious was happening, but not old enough to really understand. Sebby's younger brother, Toby, was only a few weeks old, and pretty much grew up in hospitals for the first few years of his life.

We couldn't go abroad and the holidays we did have in the UK were often cut short when Sebby was unwell. This was hard on everyone. His fifth birthday party was cancelled when he wasn't well enough to come out of hospital, and he spent Christmas Day in hospital one year, which was tough.

> **"Involving people with lived experience in shaping research helps ensure that information flows in both directions between researchers and patients."**

Having experienced first-hand the devastating impact a childhood cancer diagnosis has on a family, I knew I wanted to make a difference for others navigating a similar path in the future. That's why I joined CCLG's Patient and Public Involvement Group in 2020 to have a say in the future direction of research. Through joining this, I was able to help shape the new CCLG research strategy, which will hopefully make a huge difference to what research is done in the next five years. Its aim is to help to focus and coordinate the brilliant work done by researchers, which highlights CCLG's unique role in being able to direct research to the priorities and fill the gaps.

Involving people with lived experience in shaping research helps ensure that information flows in both directions between researchers and patients. It means researchers can focus on what matters most to patients and affects their lives during treatment and beyond. And it means patients and families can be reassured that the right research is happening and they're being listened to.

Sebby's now 11 and doing well. He still suffers from some side effects of treatment, but overall, he's great. He's loving life at school and with his friends.

As for us, we now appreciate all the little wins. For example, when he takes part in a running race in sports day at school it feels like he's come so far from the time in treatment when he had to learn to walk again. Having experienced the low times through treatment, we'll never take anything for granted.

Seirian with Amanda and her dad, Chris

How we used creativity to help us through treatment

Amanda Richards' *daughter, Seirian, was seven years old when she was diagnosed with leukaemia in 2022. Here, Amanda explains how arts and crafts helped them navigate the challenges of treatment and tells us about a special art exhibition showcasing their work.*

Before her diagnosis, Seirian had loved school and been really sporty, and was close to becoming a black belt in taekwondo. But then, in October 2022, we were given the devasting news that she had acute lymphoblastic leukaemia. Treatment at Alder Hey Children's Hospital started immediately, and it was a rocky road. Initial chemotherapy didn't work as planned, and to complicate matters Seirian suffered a clot on her brain. We were lucky enough for her to receive cutting-edge immunotherapy as an alternative, and Seirian recovered well from the clot. On 14 February this year, Seirian rang the end-of-treatment bell.

How arts and crafts helped us

Throughout treatment and long stays in hospital, we tried to remain as positive as possible and use distractions to help when Seirian felt yucky or in pain. At home we already loved drawing and crafting, so we carried on with this during our stays. Seirian loved decorating her hospital room door with art, and we both doodled during long, sleepless nights. We'd create stories about dragons and magic, eventually creating a map of all the places from our dragon tales.

Art has played a significant role in allowing Seirian to express her emotions, her pain and her joy. As a result, we amassed quite a collection of drawings, each of which has a special story or memory associated with it. Seirian also created a little joke book to cheer up other patients and included tips for coping with pain using imagination and interesting facts to share with doctors.

During treatment, we also collected Beads of Courage. These are from a charity which awards specific glass beads for each procedure that a young patient goes through. Almost 2,000 of these beautiful beads needed to be seen, so I decided to sew each one onto canvasses. This along with doodling helped me to focus on something other than the situation our family was going through. Drawing alongside Seirian gave us a combined hobby which made us laugh, challenged us, and gave us purpose.

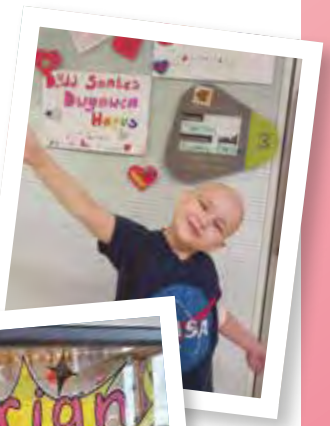
Showcasing this work

I soon realised that these pieces needed to be seen and shared. So, we launched the 'Seirian versus the Leukaemians' exhibition in July this year, with our local art gallery being the perfect venue to showcase Seirian's journey through cancer treatment. The exhibition aims to show treatment in an alternative way, conveying beauty, positivity and strength.

The response to the exhibition has been both moving and positive, and we hope to continue it in some form after it finishes in Wrexham. There's a combination of drawings, sculpture, video footage and music, all of which combine to give an insight into our world navigating the traumatic experiences of childhood cancer.

For anyone sadly going through anything similar with their child, our advice as a family would be to try and find a focus. This could be it arts, crafts, or whatever works for you, but something you can do together. Lengthy stays in hospital can be worrying, exhausting and boring. A focus can help pass the time and be used for distraction and motivation, which is vitally important when your child is feeling rotten, afraid, or emotional. We used our art to have fun, to create ways of discussing difficult subjects, and even to reduce pain with the power of imagination.

Seirian is now 10. Now chemo has finished, we're all focusing on rebuilding her strength and stamina so she can enjoy her sports and activities again. Recovery can be a long process, but Seirian's sunny outlook and desire to get better are moving us in the right direction.



▶ Seirian during treatment

Seirian's exhibition

Developing ways to identify chemotherapy resistant B-cell acute lymphoblastic leukaemia cells

Dr Elitza Deltcheva with Professor Tariq Enver

- **PROJECT TITLE:** Validating an immunophenotype of chemotherapy resistance in childhood B-ALL – towards tailored treatment and improved outcomes
- **LEAD INVESTIGATOR:** Dr Elitza Deltcheva, part of Professor Tariq Enver's lab team
- **INSTITUTION:** University College London Cancer Institute
- **AWARD:** £15,000 (funded by CCLG and CCLG Special Named Funds #TeamMax ALL Fund, Arabella's Leukaemia (ALL) Research Fund, Stand with Sofia, Elliott's Warrior Fund, Toti Worboys Fund, Harley James Reynolds Fund, Josh's Gold Star Fund, Fred Bennett's 'Don't Look Down' Fund, Henry Gloag Fund, and Eden's Fierce Fight)

Childhood B-cell acute lymphoblastic leukaemia (B-ALL) is the most common paediatric cancer. Although many children with low-risk B-ALL can be cured, this cancer is still the leading cause of cancer-related deaths in children. Current treatments are toxic, lasting up to three years, and place considerable burdens on patients and their families. While most children with B-ALL will survive, around 20% won't, either because of relapsed disease or complications from treatment. Those surviving into adulthood may suffer from long-term health problems and face fewer opportunities in life due to the disruption to their education. Therefore, there's an urgent need for early detection of the cells that cause relapse and the development of targeted, less toxic therapies.

Our previous research

With the help of Professor Tariq Enver's funding from The Little Princess Trust in 2021, our lab was able to start addressing these issues – and our efforts to understand B-ALL led to a key discovery.

All leukaemia cells are addicted to a group of proteins called the core binding factor (CBF) complex. This complex is responsible for making blood in healthy individuals. However, when the genes that encode this complex are mutated, they can cause leukaemia.

We thought that stopping the complex from working would be a good treatment for leukaemia. There's a type of drug called an 'inhibitor' that can block the activity of the complex. It can kill leukaemia cells without affecting normal blood cells, which would make it much less toxic than current chemotherapy. However, it wasn't effective enough to be used in patients on its own.

So, we partnered with a team of medicinal biochemists at the University of Oxford, who provided us with hundreds of new chemicals that could either work with our inhibitor or be more effective. We tested these on leukaemia cells in the lab, and these extensive experiments revealed five promising options that we're currently researching further.

This project

My own CCLG-funded project takes a different approach. It aims to better understand the leukaemia cells that survive treatment, as they're the ones that are responsible for relapse. However, these cells are very rare and isolating them from all of the healthy blood cells is technically challenging. Through CCLG's VIVO biobank grant scheme, we were provided with more than 50 patient samples, taken at diagnosis and after treatment.

We then used a cutting-edge method called DOGMA-seq, which allowed us look at the processes occurring in each leukaemia cell – almost as if we were using a magnifying glass. We were able to ask questions about what genes are active within each cell after treatment and investigate what makes them different. With the help of our head bioinformatician, Dr Jason Wray, we identified multiple markers on the surface of resistant cells. Together, these markers could be seen as a 'signature' of leukaemia cell presence.

Next steps

We're now collaborating with the University College London Hospital diagnostic lab to try and integrate our signature into the tests they already use at diagnosis and to monitor treatment success. We hope this will help doctors identify the cells that will cause relapse early on, tailor the treatment accordingly and, ultimately, prevent the return of the disease.

Taken together, our research can lead to improved survival rates and the development of less toxic and more targeted therapies, sparing patients and their families the distressing side effects of long-term chemotherapy. We're extremely grateful to all the families who have donated funds to CCLG and supported our research.

60 SECONDS WITH

Dr John Moppett

Paediatric haematologist at Bristol Royal Hospital for Children and CCLG member

Q: Tell us a little about your career so far?

A: I'm a paediatric haematologist at Bristol Royal Hospital for Children where I've been a consultant since 2007. I first became interested in the treatment of children with leukaemia during a year working in Sydney, Australia, where I was fortunate to work with some outstanding senior colleagues.

Whilst there I was offered a paediatric oncology job in Bristol, and I haven't moved far since. I was again super fortunate to be encouraged to undertake my PhD studies in Bristol, investigating the role of minimal residual disease analysis (MRD), an area which I still work in to this day.

Q: Tell us about your role in supporting children with blood cancer?

A: There are quite a few parts to this. I'm an active clinician taking responsibility for my patients during their treatment journey. But, on top of that, I help to lead the department in Bristol and also lead clinical trials in acute lymphoblastic leukaemia (ALL) in the UK as well as continuing to support clinical delivery of MRD analysis for childhood ALL.

Lastly, I must mention the VIVO biobank where I'm an associate director. The biobank is such an important vehicle for supporting so many of the childhood blood cancer research studies being done in the UK and internationally.

Q: What is the ALLTogether-1 trial and what is your role in it?

A: The ALLTogether-1 trial is a multinational trial involving around 14 countries in Europe, seeking to improve the outcomes for children with newly-diagnosed ALL.

At its heart is the desire to both reduce the toxicity of therapy while also increasing the chance of cure for those children at greater risk of dying from their disease. To achieve these dual aims requires a detailed understanding of each patient's risk of treatment failure.

MRD is a big contributor to this risk stratification process. I have a few roles in the trial. I helped develop the original trial protocol and in particular the MRD-based stratification, given my experience in that area. I'm national principal investigator in the UK, which largely involves lots of paperwork and explaining things in the protocol to colleagues where the protocol isn't clear (it's a very complex study).

Q: What are you most proud of in your career?

A: The fantastic teams of people that I work with, who all have children with blood disorders as their central focus.

Q: What does your job mean to you?

A: It's a life-enhancing companion during my brief sojourn in this world.

Q: Do you have a message for children and young people with cancer and their families?

A: It's a marathon not a sprint. Take care of yourselves and take hope in the ever-improving treatments that can be provided.

Oh, and keep a notepad by the side of your bed to write down all those irritating 'two in the morning' questions!

> "At its heart is the desire to both reduce the toxicity of therapy while also increasing the chance of cure for those children at greater risk of dying from their disease"

ASK THE

Expert

Sophia Landell-Wright, TYA Bone Marrow Transplant and CAR-T Clinical Nurse Specialist, University College London Hospital NHS Trust

What is CAR-T therapy?

CAR-T stands for chimeric antigen receptor T-cell therapy. It's a cutting-edge form of immunotherapy, which means it helps the body's own immune system fight cancer. Our immune system normally relies on T cells – specialised white blood cells that act as the body's soldiers – to search for and destroy abnormal cells. However, cancer cells are clever. They can disguise themselves and hide from normal T cells, allowing the disease to grow and spread. CAR-T therapy overcomes this problem by giving a patient's T cells a new 'target' enabling them to recognise cancer cells more clearly and attack them with precision.

Why is it used?

CAR-T therapy is mainly used when standard treatments such as chemotherapy, radiotherapy or targeted drugs haven't worked, or when the cancer has returned after a period of remission. Doctors call these situations relapsed (the cancer has come back) or refractory (the cancer hasn't responded to treatment).

In some cases, CAR-T can be used after a bone marrow or stem cell transplant, and occasionally even before a transplant if other options are limited. For many families, this treatment represents hope when other therapies are no longer effective.

How does the treatment work?

CAR-T therapy is a multi-step process that usually takes several weeks and requires a hospital stay...

1) Collection: T cells are removed from the patient's bloodstream through a process called apheresis. This is similar to a long blood donation, where blood is drawn from the body, the T cells are separated, and the remaining blood returned.

2) Modification: In a specialised laboratory, scientists insert a new gene into these T cells. This gene creates a receptor on the cell surface called a chimeric antigen receptor (CAR). The CAR acts like a sensor, enabling the T cells to recognise specific proteins found on the cancer cells.

3) Infusion: Once enough modified cells are produced, the patient is admitted to hospital. A short course of chemotherapy is given first to reduce existing immune cells and create space for the CAR-T cells. Finally, the engineered T cells are infused back into the bloodstream, where they multiply, hunt down, and destroy the cancer.

Are there any side effects?

Because CAR-T cells trigger a powerful immune response, there are some side effects –

- **Cytokine release syndrome:** A surge of immune chemicals can cause fever, low blood pressure, or breathing difficulties
- **Neurotoxicity:** Some patients may experience confusion, headaches, or seizures as the immune system affects the brain

These reactions can sound alarming, but treatment takes place in hospital under very close supervision, and doctors have effective medicines to manage them. Patients also experience the usual side effects of chemotherapy, such as fatigue or low blood counts.

Who can receive CAR-T therapy?

At present, CAR-T is approved in the UK for certain blood cancers, including specific types of leukaemia and lymphoma, particularly when other treatments have failed. Researchers are running clinical trials to see whether this approach can also help patients with solid tumours, such as brain tumours or sarcomas.

Where is it available for children and teenagers in the UK?

CAR-T therapy for young people is currently offered at four specialist centres:

- Great Ormond Street Hospital, London
- Royal Manchester Children's Hospital
- University College London Hospital (UCLH)
- Great North Children's Hospital, Newcastle

These centres have the expertise and facilities to deliver this highly specialised treatment safely.

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