CCLG The Children & Young People's Cancer Association

Childhood Cancer Awareness Month

FREE

AUTUMN 2025 | ISSUE 108

contact

MAGAZINE

Hope

What does hope look like to different people? What work is being done to offer hope to children and young people with cancer, and by whom?

+ IMPROVING QUALITY OF LIFE FOR SURVIVORS

+ INCORPORATING LIVED EXPERIENCE IN RESEARCH

Family Story

Sam Price, grandfather to **Sorrelle** who was diagnosed with leukaemia 10 years ago, tells us about the role he played as a grandparent in supporting her, and his hopes for a book he's written about her treatment **Page 6**

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Autumn 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

www.cclg.org.uk

KEEP IN TOUCH

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Your messages...

On Contact's recent editions...

Olly's story provides hope and inspiration

"Thank you for sharing Olly's journey, what an inspiring young man."

"Olly, we think you're amazing. Totally and utterly inspirational."

"Thank you, this is so motivating."

Read Olly's article here: **https://bit.ly/3IM7zcV**

Becky's article on the importance of play specialists resonates with readers

"Becky was one of the first people we met when our son was diagnosed, and she made the journey so much easier for us. She is massively there for the parents, too. Explained things so clearly for us. The children love her. An amazing part of the team at Sheffield Children's Hospital, we will be forever grateful for the help she gave to us."

Read Becky's article here: **http://bit.ly/4fgcZsz**

CCLG's information resources continue to provide vital support

"Thank you CCLG: The Children & Young People's Cancer Association. You have provided us with really helpful resources during and after treatment."

Praise for CCLG's research webinar on fertility preservation

"The presentation was informative, well-structured, and addressed a topic that is both sensitive and incredibly important for patients and families navigating cancer treatment."

Hello!

Hope can mean different things to different people, and that meaning can shift over time. It's often deeply personal and can influence a cancer journey through diagnosis, treatment and recovery. Hope can also be fragile, especially if treatments fail or prognosis worsens. But even then, it can shift focus, from cure to comfort, and quality of life.

Hope can be nurtured through support from family, friends, and healthcare providers, and by hearing the experiences of others who have harnessed it. In this edition, we hear from many different people who have navigated the world of children and young people's cancer, and what has given them hope, even in the most challenging of times. We also hear from researchers and professionals on why, with new initiatives and pioneering research, there's reason to be hopeful for the future.

Sharing the stories of children, young people and their families, and what helped them bounce back from setbacks and challenges, shows that even in the face of uncertainty, hope can be a powerful force. When navigating the challenges of cancer, it can help find meaning and joy in the face of adversity.

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

Dr Ren Manias

Consultant Paediatric Oncologist at Southampton General Hospital and CCLG member

Hope is a word we often encounter in children and young people's cancer, though not always in the ways we might expect. For many families, hope begins with the question of cure – of whether treatment can work, and whether life might eventually return to something that resembles the time before diagnosis. And, in many cases, that hope is well-placed. Thanks to decades of research, collaboration and clinical progress, survival rates for many cancers have improved considerably. For some diagnoses, we are now beginning to consider not only how to treat more effectively, but how to reduce the burden of treatment itself.

As anyone involved in this field knows, however, the story is rarely straightforward. There are those for whom treatment is prolonged or more complex than anticipated, and those contending with the effects of relapse, late effects, or long-term uncertainty. In these situations, hope doesn't disappear, but it shifts – sometimes subtly, sometimes starkly. It might become focused on completing a particular stage of therapy, on accessing a clinical trial, or on preserving fertility for a future that still feels possible, even if it looks different from the one originally imagined.

There are also times when the focus of care must change entirely. When curative options are exhausted, we do not speak of abandoning hope, but rather of recognising that it now rests in different places. It may centre on comfort, on time spent at home, or on the ability to make decisions that reflect a child or young person and their family's values. High-quality palliative care is not a last resort, but an active, skilled and compassionate approach to care that respects the complexity of this phase and supports families with clarity and honesty.

At a wider level, the work continues. Research is aimed at accelerating progress, not only in treatment outcomes, but in supportive care, long-term survivorship and equitable access. These are not abstract goals – they're informed directly by the realities that families face every day, and by the need to ensure that progress is meaningful across the whole spectrum of experiences.

Hope, then, is not static. It's shaped by evidence, by the conversations we have with families, and by our willingness to adapt when circumstances change. Our responsibility is not to define hope for others, but to help make space for it – in whatever form it may take.

NEWS IN BRIEF

AI model improves prediction of brain cancer relapse in children

A study from Harvard University shows that using an AI tool to analyse multiple brain scans over time can predict relapse in children with gliomas far more accurately than traditional methods. Using temporal learning, a technique which allows AI to understand things chronologically, the model could correctly predict whether a child would relapse within a year to around 75–89% accuracy. Current methods are only accurate to around 50%. Researchers hope the tool will help identify high-risk patients early, leading to better, more personalised care.

(Source: The Harvard Gazette)

New understanding of genomics could lead to new treatments

Cambridge researchers have shown that childhood cancers like Wilms tumour are much more complicated than previously thought. Using advanced single-cell sequencing, the scientists found Wilms tumour cells had hundreds more genetic mutations than expected, challenging long-held beliefs that the genetics of children's cancers are simpler than those of adults, with fewer changes between healthy cells and cancer cells. The findings could lead to new treatments and may mean treatments currently only used for adult cancers, such as some immunotherapies, could be effective in some children.

(Source: Cambridge University Hospitals)

Psychological factors linked to early pain in children with cancer

American researchers identified factors that can be linked to increased pain during the early stages of treatment. While some factors were medical, such as age or gender, there were also psychological risk factors. They also found that pain was more disruptive for children from lower-income families, those with higher fatigue, or whose parents are experiencing high levels of stress. The findings could help doctors manage pain better by approaching care holistically.

(Source: Frontiers in Psychology)

Genetics and treatment drive later cancers in childhood cancer survivors

Research has found that both cancer treatment and genetics play key roles in whether a childhood cancer survivor will develop a second cancer. Analysis of long-term data from over 12,000 survivors found a combination of radiotherapy and high genetic risk explained most cases of later cancers. In contrast, lifestyle factors like smoking or diet had little impact. Findings show that treatment history and genetics should be considered as part of follow-up care.

(Source: The Lancet Oncology)

“Through therapy and time to reflect, I started to become hopeful again”

***Sophie Cohn** was 17 years old when she was diagnosed with stage four Hodgkin lymphoma in November 2019. Now 23, she tells us about the effects of her cancer, what has helped her process her experiences, and how there’s hope for life after treatment.*

Looking back now to when I was diagnosed with cancer, I realise how terrified I was. I was 17 and in my final year of my A-levels and wondering how this would impact my life. However, at the time, I don’t think I fully processed the news and didn’t for a while afterwards, either.

Sophie submitting her university dissertation

Treatment was six rounds of chemotherapy, and three weeks of radiotherapy, over the course of seven months. Aside from the anticipated side effects of vomiting and general fatigue, there was the hair loss. Losing my hair was huge and made me feel hopeless. It was such a prominent sign that I was sick, and, in my eyes, it was the first thing that everyone noticed when they looked at me. On top of this, I also contended with a side effect known as ‘chemo brain’. I can only describe this as a sort of brain fog. All the tools I needed to produce the right thoughts or sentences were there, I just felt like I didn’t really know how to use them anymore.

From the day I was diagnosed to the day that treatment ended, my mind went into a form of autopilot. All I was focused on was first getting through chemotherapy, and then radiotherapy. There was no time for me to feel emotional about it. Whether this was the healthiest way of dealing with what I was going through, I couldn’t say, but it did leave me with a lot of suppressed thoughts and feelings once I was in remission, which all, eventually, came crashing down. A few months after I received the all-clear, I finally had time to process what had happened to me. And, although most of the physical side effects had subsided, the mental ones were very much still present.

Through therapy sessions and simply just time to reflect, I started to become hopeful about my future again. The chemo brain stayed with me for a few years, but the fog did clear, if you’ll pardon the pun. I became hopeful as the further away I got from the period I was ill, the more I was able to see that I was, and still am, so much more than my illness. It was not the only thing people saw when they looked at me. To most people I was just ‘Sophie’, not ‘Sophie who had cancer’. Reflecting on my experience offered me hope, as did support from all those around me, both during and after treatment.

Since being diagnosed, I’ve graduated from university with a degree in Geography, travelled to some incredible places, got a job in consultancy, and have felt like my old self again. However, I still acknowledge and embrace that having cancer has formed a large part of who I am today.

When I was going through treatment, seeing articles like this, showing that there’s hope to get through what’s one of the worst things imaginable for a young person, really helped me. It showed I was not my diagnosis, prognosis, or medical outcome. I was who I’d always been with a few (big) health complications. The journey through having cancer as a young person isn’t a smooth one and certainly doesn’t end as soon as you ring that little bell, but I like to think that the souvenirs I carry from it make me a better and stronger person.

Sophie during treatment

▶ Sam with Sorrelle on the radio

"The hardest voyage I've ever been on"

***Sam Price's** granddaughter, **Sorrelle**, was diagnosed with acute lymphoblastic leukaemia in 2015. He tells us about the role he played as a grandparent in supporting her, and his hopes a for book he's written about her treatment.*

Sorrelle is now 10 years old, but her start in life wasn't normal. When 10 months old, she was staying overnight with us. She seemed a little quiet that evening, not as smiley or hungry as usual. I took Sorrelle back to Gemma, her mum and my daughter, and mentioned she seemed a little out of sorts. Gemma kept an eye on her, noticing some slight bruising on her cheek later that day.

On a mother's instinct, Gemma took Sorrelle to hospital. At 11:30pm on 22 August 2015, my phone rang, and it changed my life. What I heard will haunt me for ever: "Dad, they think it's leukaemia." The next morning, we entered what would become home over the next three years: Manchester Royal Children's Hospital oncology ward.

I soon realised I couldn't protect my family from this, but I could get them through it. Watching my daughter's anguish and my granddaughter's pain was incredibly hard. I felt useless against this disease, and the feelings of frustration, anger and sadness were overwhelming. I wanted to scream, punch walls, and find something, or someone, to blame. However, I soon came to see that all of that was futile. Instead, I realised the part I had to play, which was every bit as important as the chemotherapy, the transfusions, the bone marrow transplants, the antibiotics, and all the other medicines or procedures.

The role I played in supporting my family

I determined my role to be that of a court jester, occupying the corridors of the ward, Sorrelle's cot-side, anywhere she was, with the job of simply making her smile in any way I could. This, I found, helped my granddaughter cope, but also gave my daughter some respite. She was able to watch her daughter laugh and smile and the consequence was that, for moments, Gemma was able to smile, too.

I discovered that using cardboard urine bowls as hats can make a child howl with laughter to the point nurse's attend. I watched endless kids' movies, drew thousands of pictures, pulled endless funny faces and then, driving home, let my guard down a little emotionally, before putting a smile back on, determined to carry on. No matter how devastated I was, or how much my heart ached.

There were dark moments. But I trusted the science, even if I did find myself questioning, not to confront but to explore, her consultant, Professor Robert Wynn, the most eminent and saintly man I've ever met. There were so many people who helped during treatment, from our 'ward family', to all the doctors, nurses and other medical professionals. Everyone helped save a little girl and, in turn, save a family, helping us to re-prioritise our lives, and allowing us to look again at what's important.

Sorrelle and her consultant, Prof Wynn

So, this was the train that hit us. What would my advice be to any grandparent finding themselves in the same situation? It sounds simple, and during this chaos it can feel like the most impossible thing, but just be you. That's all Sorrelle needed, and that's all Gemma needed, too. The skill is recognising you can't change a thing. So, be yourself, be the grandparent and parent, do what you've always done. Recognise that unless you're Professor Wynn, or others like him, you can't cure cancer – and no one expects you to.

Your child simply needs a hug, the reassurance you've given them for years, a presence to be there and support them through it all. Your grandchild needs a hug, so don't be afraid. I wasn't going to break Sorrelle, so I got in there and hugged that beautiful little girl, my sidekick, my soon-to-be comedy partner. And here's the strangest thing of all: something you never think will happen at the point of diagnosis, you really can find laughter on a children's oncology ward. They're still children, they still want to play, they still laugh, even when poorly and dealing with huge things.

"My phone rang, and it changed my life. What I heard will haunt me for ever: 'Dad, they think it's leukaemia'."

What life looks like now for Sorrelle

We all wear the scars of childhood cancer: Sorrelle the physical, and the rest of us the emotional and mental. Sorrelle didn't just deal with leukaemia, she had bowel surgery, a stoma for six months, sepsis, septicaemia, adenovirus, two bone marrow transplants, and endless transfusions. Because of treatment, Sorrelle has conditions that will stay with her, including thyroid issues, chronic kidney disease, hearing loss, and calcium issues. But, the cancer's gone, and she's happy, funny, clever and engaging.

She's the best of us, and my best friend. The bond we have just can't be measured. We laugh together, understand each other, talk together, and ponder life together. She's the most philosophical 10-year-old I know!

How I developed a book about our experiences

During Sorrelle's treatment, I sent daily messages to our extended family across the globe. Although no great fan of Facebook, I used it to record all these messages. Gemma kept them all and some years later, I decided I wanted to write a book, made up of the 69,000 words of messages over that three-year period.

I wanted to give Sorrelle something to read when she's older to help her understand and prepare her for any issues she may have in the future. I also wanted to help those families who find themselves in this impossible situation with little understanding of how their world will change, in an informative, but not alarming, way. If just one person reads a single sentence and asks a question they wouldn't have thought about, which then saves a life, then it'll all be worth it. Finally, I wanted to generate funds specifically for the ward that saved Sorrelle. The royalties from the book are helping to buy items for the ward that can help make a family's journey a little more bearable.

And so, I began the process of writing the book, with its title, 'Small Boat in a Big Ocean', taken from a song that became my daughter's anthem during Sorrelle's treatment. Eighteen months later, in December 2024, the Lord Mayor of Manchester joined us to launch the book. Copies have been bought in the UK, USA, Poland, Canada, and Greece. We've received letters of thanks from Kensington Palace and auctioned special signed copies by sporting icons.

Sorrelle now happily autographs copies of the book and together we attend 'meet the author' events. We're trying to do some good, and the most pleasing thing for me is that Sorrelle is developing compassion and kindness, things that our world could certainly do with more of.

It's taken time, a sizable financial commitment and energy to get to this point, but I wouldn't change a thing. I'm passionate about providing whatever support and awareness I can when it comes to childhood cancer. In addition, Sorrelle and I have, for the last six years, visited the ward every Christmas with gifts for the children. It's our personal acknowledgement as to just how difficult that time of year can be for families who have to be on the ward during the period.

A final message

I would like to finally add on a personal note that should you find you need to speak with someone, please seek them out and talk. The greatest lesson I learned in being there for my family was that I had to take care of myself, too, or else I'd be no help to others.

Book launch with the Lord Mayor of Manchester

Small Boat in a Big Ocean is available to buy from Amazon and Waterstones.
www.smallboatinabigocean.org

Hope for the future: Preserving fertility in young cancer patients

Dr Mark Brougham

Prof. Rod Mitchell

Dr Mark Brougham *and* ***Professor Rod Mitchell*** *are part of the Edinburgh Fertility Preservation team, a group of clinicians and scientists working to develop procedures for fertility preservation in children, teenagers and young adults. They explain what fertility preservation options are available for young cancer patients.*

Being told you, or your child, has cancer is hugely frightening, and naturally the first thought is usually about getting better. The future suddenly becomes uncertain, but discussions about diagnosis and treatment lead to consideration of long-term implications. While fertility may feel like something to worry about later, it needs to be thought about before any treatment starts. Follow-up studies of cancer survivors show that infertility is one of the most distressing long-term side effects, including feelings of regret at not trying to preserve fertility before treatment started.

What do we mean by infertility?

It's important to consider what we mean when we talk about fertility. Boys who haven't yet gone through puberty don't make sperm that can fertilise an egg. However, their testes contain 'spermatogonial stem cells', from which sperm will be made when they're older. These can be permanently damaged by some cancer treatments, which means they'll never make enough sperm of their own. However, the cells in the testes that produce the male hormone testosterone are much less likely to be damaged. Therefore, they can go through puberty and grow normally, but may not be able to have a baby naturally.

Girls are born with all their eggs in their ovaries, and this 'reserve' goes down throughout life until menopause, when periods stop and no further eggs are released. The timing of menopause varies due to many different factors, including genetics. If your mother had an early menopause then you're more likely to have one. The average age of menopause is around 51. Some cancer treatments cause the egg supply to go down faster than normal, which means menopause will occur earlier.

This might mean considering trying for a baby earlier in life, in case menopause occurs early. Some treatments cause the ovaries to stop working at a very young age, and therefore having a baby naturally may not be an option. An early menopause also results in other health issues, which can be helped by hormone replacement therapy (HRT).

The effects of treatment are difficult to predict so it's very important not to assume fertility has been affected by treatment. Contraception should still be used if a pregnancy is not desired.

There are many ways to help assess fertility, but most are only helpful once puberty is finished. For males who have gone through puberty, measuring the volumes of their testes in clinic can be a good guide as to whether sperm are being made. Blood tests measuring hormone levels can also be useful. A sample of semen can be sent to the lab to analyse numbers of sperm and how well they move. If fertility hasn't been significantly affected by previous cancer treatment, there shouldn't be further decline.

For females who have gone through puberty, regular periods are a sign that the ovaries are functioning well. However, it can take time for periods to become regular after any chemotherapy. The volumes of the ovaries can be measured using an ultrasound scan and hormone levels in the blood can also be measured. Anti-Müllerian Hormone (AMH) can be a useful indicator of how many eggs are left, but it isn't clear-cut and measurements before or during puberty can be difficult to interpret.

Discussing fertility at diagnosis

There are huge amounts of information to take on at diagnosis. Side effects of chemotherapy can feel overwhelming. However, when cancer survivors reflect on these discussions, many say the information they received on fertility wasn't enough to help them, and their families, decide what to do. It's therefore important that the healthcare team discuss fertility with patients and families. This should include what problems may happen and, particularly if there's a high risk of infertility due to treatment, what can be done now that may help in the future.

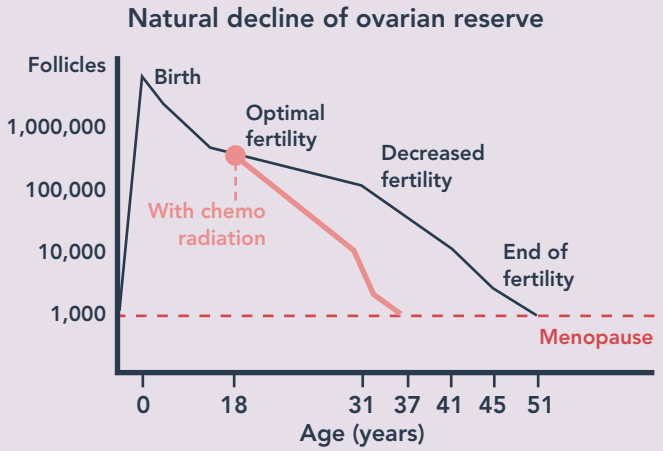
Who's at risk?

It's important to remember that not all cancer treatments cause infertility. Radiotherapy that includes the testes or ovaries is particularly damaging, with a very high risk of future infertility and, for women, early menopause. Some chemotherapies cause very little damage to testes and ovaries, but others do cause infertility in later life. However, the amount of damage depends on the total dose given and can be very difficult to accurately predict. Your healthcare team should explain to you how likely future fertility will be affected, but it's important to remember

this represents a 'best guess' based on treatment, whereas other factors will also affect future fertility, such as genetics, diet and smoking.

Most of the evidence we have about cancer treatments and their effects on fertility come from follow-up studies, based on assessing fertility in people who have received these treatments many years ago. Increasingly, 'newer' treatments for cancer are being used, such as immunotherapy, which uses the immune system to treat cancer – for example, with antibody treatments and CAR-T, and enzymes targeting growth factors in cancer cells. Because these haven't been given to children until relatively recently, we don't yet know what effects these treatments may have.

Figure 1: *A graph showing how the number of eggs in the ovaries go down from birth until the menopause, and how they may go down more quickly with some cancer treatments.*



What can be done?

For many, future fertility may not be at sufficient risk to justify performing procedures to preserve fertility, particularly if these require extra surgery. However, if fertility may be at risk, it's very important to consider what can be done to protect or preserve fertility before any cancer treatment is given, otherwise, it might be too late. Cancer can cause symptoms that may be life-threatening, such as a tumour affecting breathing or the spinal cord, or may be affecting vision. In such circumstances, emergency cancer treatment may be essential, meaning fertility preservation isn't possible.

Established techniques

For males who have gone through puberty and are able to produce a semen sample by masturbation, sperm can be stored before any cancer treatment, for future use. This is established and should be offered to all suitable patients. However, for some young patients who have just been told they have cancer, this can be difficult to do, and semen samples at this time often don't contain enough healthy sperm.

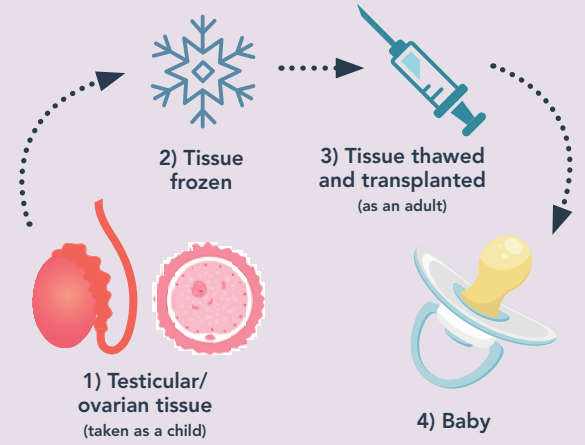
For females who have gone through puberty and have a partner with whom they want to start a family, eggs can be produced from the ovaries and fertilised using the partner's sperm by in vitro fertilisation (IVF). The embryos can then be stored and, in the future, put back into the womb. This can be very successful. For mature females who don't have a partner, eggs can be produced and stored for future use, which is established but works less well than storing embryos. Unfortunately, both techniques require hormones to be given to stimulate the ovaries before eggs are harvested. This can take several weeks, which will delay cancer treatment. Because of this, it's often not appropriate to consider this for young cancer patients.

Experimental techniques

Because ovaries contain eggs for the future, part or all an ovary can be removed with an operation before cancer treatment and stored for future use. This can be done at any age. This has been done for many years and has been successful, with babies born as a result. However, it remains experimental as we're still learning how best to use the ovarian tissue, particularly when it's taken before puberty. Surgery to get the tissue at the start is also significant and a lot to go through at a time when so much else is going on. The operation is usually done using a 'keyhole' approach, under the same anaesthetic as other procedures, such as putting in a central line.

Boys who haven't yet gone through puberty don't have any sperm to store but they have 'stem cells' in their testes. Taking a small piece of one of the testes may contain enough of these stem cells to store. In future, it's hoped that sperm can be made from these stem cells, which can then be used to make a baby using techniques like IVF. However, this is very experimental, and no babies have been made in this way yet, but research is rapidly advancing so it's hoped this will be successful in the future. Because this is experimental, it's important it's only done as part of a carefully monitored research programme and should only be offered to appropriate patients at very high risk of future infertility, with careful counselling and consent.

Figure 2: *A diagram showing how part of an ovary or testis can be taken before any cancer treatment and then used in the future to help have a baby*



Sexual health

Survivors of childhood and young person's cancer can have problems with different aspects of sexual health. It's important to remember that fertility and sexual health are different. Your fertility may not be affected but you may have problems with sex, and equally you may have problems with fertility but no problems with sexual activity. These are issues that are important to discuss with your healthcare team.

SMILE: an international research group improving quality of life for childhood cancer survivors

***Professor Mark Gaze**, **Dr Shermaine Pan**, **Dr Marinka Hol** and **Professor Marianne Aznar** are part of the SMILE consortium, an international research group dedicated to minimising the long-term impact on the teeth and face in childhood cancer survivors. Here, they tell us about the group's work.*

When a child or young person is diagnosed with cancer, every family clings onto one hope above all else – a cure. The journey to cure, however, is often long and complex, involving multiple treatments such as surgery, chemotherapy and/or radiotherapy. At the start, parents are presented with an overwhelming amount of information, with more details emerging as treatment progresses. Long-term side effects are mentioned during the consent process, but it can be hard to fully absorb the potential challenges ahead, as there's a rush to begin, hopefully, curative therapy. Cure rates for many childhood cancers are high, but for some cancer types, the cost of survival can be significant, leaving children with physical and psychological challenges.

For example, consider cancers arising in the head and neck region, such as rhabdomyosarcoma. Late effects depend on the age of the child at diagnosis, tumour location and size, and whether it has spread (to lymph nodes in the neck, for example), and critically, the type of treatment received. Both surgery and radiotherapy can cause immediate or delayed problems. The resulting problems include, but aren't limited to, deafness, visual loss, hormone deficits, difficulty opening the mouth fully, teeth loss, dental problems, speech and swallowing impairment, and facial deformities. For decades such treatment-related effects were regarded as "the cost of cure" – something families were expected to accept as part of the child's survival. But, encouragingly, things are changing.

What is SMILE?

SMILE is an international collaboration of clinicians and scientists working to better understand, reduce and manage the long-term impact of head and neck cancer treatment in children and young people. It brings together experts from different fields – paediatric and clinical/radiation oncologists, head, neck and dental surgeons, clinical scientists, physicists, researchers, and late effect clinicians with a shared goal: to improve outcomes for survivors, both medically and their quality of life.

Since 2023, SMILE has hosted an annual meeting in Manchester bringing together specialists with an aim to:

a. **Investigate** – learn more about how dental and facial changes after treatment affects childhood cancer survivors physically, emotionally and in daily life
b. **Integrate** – use the knowledge to develop evidence-based guidelines, to improve clinical care
c. **Innovate** – develop better treatment strategies to improve treatments and long-term care, ensuring survivors thrive, not just survive

SMILE is committed to raising awareness, by highlighting the challenges survivors struggle with. Importantly, we're also committed to supporting survivors, ensuring that those already living with lifelong effects receive the care and attention they need. The answers aren't easy and even with advances in treatments, many survivors still struggle with daily challenges that impact their quality of life.

SMILE is a long-term initiative, one that requires continued research, funding and collaboration. Progress has already been made, with successful research grants and scientific publications, but more work is needed to ensure every child who survives cancer has the chance to live life to the fullest.

Our mission goes beyond survival – we strive to ensure childhood cancer survivors thrive. We work closely with patient and parent focus groups to better understand and address the long-term effects of head and neck treatment. If you, your child, or someone you know has experienced facial or dental effects following radiation therapy and would like to be part of this initiative, we'd love to hear from you. **Please contact smile.consortium@manchester.ac.uk**

Michael

“Life has thrown me challenges but I’m proud of how I’ve overcome them”

Michael Omotayo *was diagnosed with retinoblastoma, when he was two years old in 1995. Now 32, he tells us about his journey from a young child with cancer to becoming a personal trainer and sports performance coach, including the challenges he’s faced and how he’s overcome them.*

I was diagnosed with cancer after my mum noticed a white glow in my left eye. She initially took me to several opticians, who didn’t see a problem. She was then referred to a specialist eye and vision doctor, which is where the condition was noticed. By the time it was detected, the tumour had grown very large, so the best option was to remove my left eye, and have an artificial eye made for me to wear in place of it.

My experience growing up with retinoblastoma was generally positive. I was very aware that I only had one eye, and I knew this meant I was different to many other children. Despite this, my parents did a great job of letting me know I was still ‘normal’ and could excel just the same as if I had both. Being the youngest of three children also helped as my older siblings were very protective and looked out for me.

At an early age, the biggest challenges came from other children asking if I had a lazy eye and the rare instances where another child had made fun of me. This certainly didn’t paint a picture of how I was treated overall by other children, and I formed many friendships.

Retinoblastoma had little to no effect on my ability to succeed in education. I remember the teachers having to get books for me to read from the older years when I was in reception, and I also loved maths. During primary school, my main hobby was playing the trumpet in which I achieved a grade 5 by the time I was 11 years old. Overall, I took pride in my education and achieved great results in my GCSEs and A Levels. After college I went to university to study Mechanical Engineering and graduated with a 2:1.

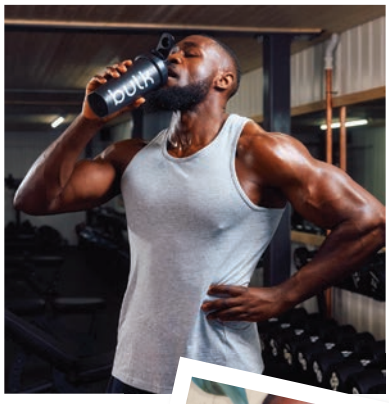
“My advice to young people navigating life after retinoblastoma, or any cancer, would be to try not to let it hold you back.”

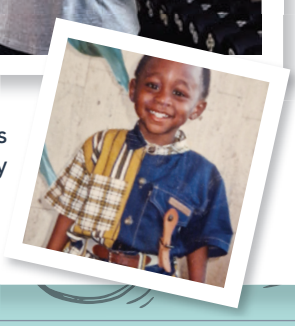
I developed a passion for sports from an early age and over the years, I enjoyed playing football, rugby and basketball. After university, I embarked on a challenging American football journey, during which I dislocated my left ankle, resulting in me having to undergo several surgeries. Despite this, I was determined to push myself through a difficult recovery period and ended up competing and performing well at some showcases in America. Playing sports with one eye was somewhat challenging, but I was very talented.

The challenges were mostly based on having no peripheral vision on my left side. To help combat this, I had to train extra hard to improve my balance, stability and reaction times.

Today, I’m proud of the man I’ve become. Life has thrown me various challenges, and I take great pride in having been able to overcome them. I’m very secure in myself, formed many great relationships, and many people often forget that I have one eye! I’m currently a personal trainer and sports performance coach which has allowed me to combine my love for sports, health and fitness, my experiences with overcoming obstacles, and my passion for helping others.

My advice to young people navigating life after retinoblastoma, or any cancer, would be to try not to let it hold you back. Despite the difficulties you face, you must try to stay strong and allow them to motivate you. Overcoming adversity in life in any situation is very rewarding, but doing so with a ‘limitation’ will give you that extra self-confidence and belief that’s needed to navigate through life. Turn your limitation into your superpower and keep going!





▶ Michael as a young boy

"I'm beginning to realise my dreams"

***Lewis Paget**, now 26, was diagnosed with two different leukaemias at the same time as a teenager in 2016. Here, he describes the impact of this, and how it has influenced him to become a cancer researcher himself.*

My name's Lewis and I'm just an ordinary young man with an extraordinary story to tell. Mine and my family's lives changed for ever a week after I turned 17, when I was diagnosed with acute lymphoblastic leukaemia and acute myeloid leukaemia simultaneously. My story really starts on my birthday, when I woke up with a butterfly rash on my face. Before I knew it, I was being dragged down to the GP by Mum for further investigations, which was hardly an ideal start to my celebrations. Nevertheless, the GP confirmed Mum's suspicions that it was dermatitis, and we all assumed that would be that.

However, as it turned out, my body had other ideas…

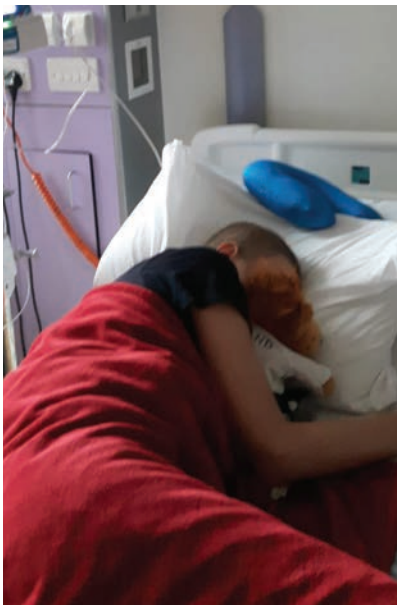
Over the next few days, the rash persisted, and I started to deteriorate. I stopped eating and drinking, and felt nauseous and dehydrated. Eventually, after multiple days without food and little fluid intake, I was admitted to my local hospital and less than 24 hours later I was diagnosed with a life-threatening disease. It's worth remembering at this point that I was a relatively healthy teenager with no previous medical complications, so how on earth had I found myself in this position?

The only way I can begin to describe what receiving a cancer diagnosis is like, at any age, let alone as a teenager, is by imagining your family being represented as a jigsaw, with that jigsaw being thrown up in the air and chaos then ensuing. Heartbreaking, terrifying, earth-shattering, even. My family and I had suddenly been transported into a world of unknowns and the only thing I knew for certain, was that life was never going to be the same again.

So many challenges lay ahead, with so much to process and no time to do so, as was dictated by the nature of the beast we faced. While in hospital, we were constantly bombarded with information and decisions to make, by countless medical professionals wanting to conduct tests or procedures. It was a confusing time and quite overwhelming. Then there were the treatments themselves: chemotherapy, radiotherapy, a bone marrow transplant, and a period in intensive care mixed in for good measure!

The impact of my cancer

As you can probably imagine, all of this had a devastating impact on my physical, psychological and emotional wellbeing. Physically, I was absolutely battered for months on end. Equally, my mental wellbeing took a monumental hit. The psychological side of being in hospital and the associated isolation took a huge toll, not to mention the processing of everything in my recovery, which was another minefield to navigate.

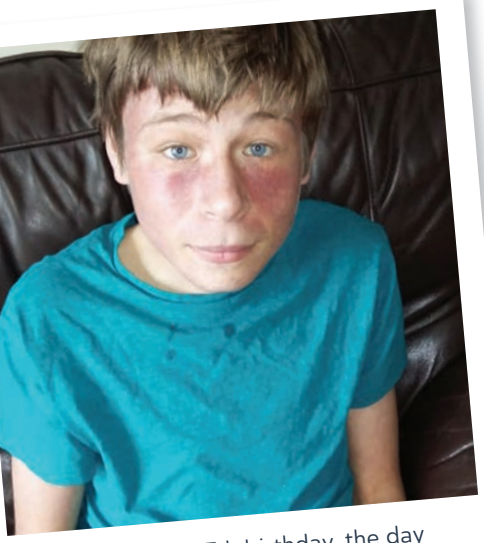


I don't mind admitting that I ended up in some very dark places. Honestly, I have no idea how I managed to overcome these challenges, but having the most incredible support network anyone could ever ask for most certainly helped.

> "My experiences have driven my career choices to date as I aspire to work in cancer research labs, with my ultimate dream to find a cure."

Nurses, consultants, social workers, counsellors, other health professionals, friends, and, of course, my family, headed up by my truly remarkable mother, all played a huge part. How my mum managed to maximise her time with me, conducting an ever-present vigil at my bedside, while also single-handedly parenting my two brothers and coping with a full-time job, is barely fathomable. She was, and still is, my ultimate inspiration and I'll never be able to truly express my gratitude as there aren't enough words in the English language.

Equally, right from the outset, we always had a sense of hope instilled within us and I simply can't overstate the importance this had. Arguably, it was this, that even in the darkest of moments, enabled my family and I to pull through. This was enhanced further by having the unique opportunity to witness first-hand, just how far fellow



Lewis on his 17th birthday, the day he first showed signs of cancer

human beings were prepared to go to save my life. I've had the privilege of experiencing just how sacred human life is and subsequently, the very best aspects of humanity.

How cancer and its treatment has influenced my life

My experiences have driven my career choices to date as I aspire to work in cancer research labs, with my ultimate dream being to find a cure. Cancer took so much from me, and I'm fuelled by this injustice as I relentlessly strive to right those wrongs.

My determination has been unwavering, working tirelessly through two sets of A-levels and two separate degrees, in order to make my dreams a reality. All of this is in the hope that I can change the lives of future generations of cancer patients for the better.

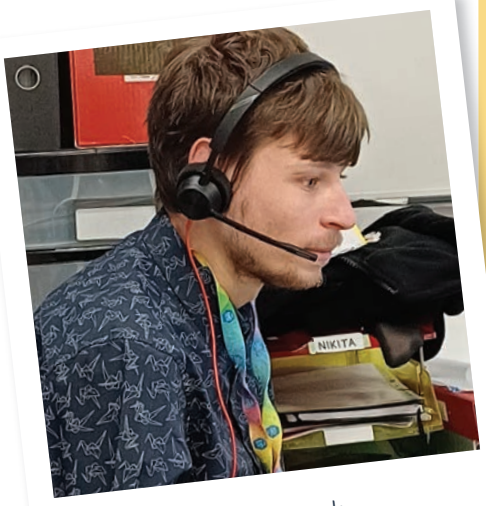
Similarly, in recent years, I've become a passionate advocate and even an ambassador for young cancer patients through my volunteering for multiple cancer charities including CCLG, Young Lives vs Cancer, Anthony Nolan, and many more. I have enthusiastically raised awareness of the incredible work that each of these charities do, as well as of cancer in young people more generally, as this is terribly lacking in wider society. Additionally, I've shared my lived experiences in the hope of influencing change, so that future generations of young cancer patients don't have to endure as much adversity.

What life looks like now

Life's far simpler for me now. I'm nearly nine years post-transplant with no recurrence of my cancer. Apart from the odd episode of chronic fatigue, which is wholly expected given my intense treatment, I'm able to live a relatively normal life with few complications. This is something which I'm immensely grateful for and I'm regularly reminded of just how lucky I am. Furthermore, I'm beginning to realise my dreams as, in a full circle moment, I'm currently working in the research department of the very same hospital I was treated at. I've even had the opportunity to work with a few of the consultants that looked after me!

Final thoughts

Firstly, I believe my story is one of hope and reflection. Therefore, I hope that by sharing my story I can empower more young people to share theirs and have a similar mindset. Secondly, no matter how difficult life seems, never give up as nothing, and I mean nothing, is ever impossible. If someone ever tells you that you're unable to do something, don't listen and do everything in your power to prove them wrong!



Lewis at work

Lewis volunteering

My life isn't always perfect but it's a life I'm grateful to have

Rosie Lazar *was diagnosed with acute lymphoblastic leukaemia (ALL) aged two in 1996. Now 32, she tells us about her cancer treatment as a child, what life looks like now, and why she wants to give back to charities like those that helped her.*

I'd always been an active child, but before my diagnosis, Mum noticed I started getting tired quickly during our daily trips to the park. It was like I had flu symptoms that just wouldn't go away. My family GP back home in Australia was quick to arrange tests, and what followed was my mum and dad being given probably the worst news any young parents can imagine. During treatment, I went through two years of various chemo drugs. I lost my hair twice. I developed pneumonia twice. The second time, doctors told my parents I might not make it.

I'm very lucky, in that I don't have many memories of this time at all. What I do remember is the kindness of the nurses at the hospital, who played Disney's 'A Whole New World' on a tiny CD player to distract me from spinal taps. I remember the Mickey Mouse stickers on the hospital corridor walls and how blinding the sun felt after a long stay. And I'll never forget my consultant, who was so gentle and caring.

I started primary school a little later in the year than the other children, and I had extreme long hair envy. It was no surprise to my parents when I quickly became best friends with a red-headed girl with a long, thick Jasmine-style braid. Other than that, the rest of my childhood felt very normal. I didn't really think of myself as different to any other children.

Later, I realised that there were small signs of trauma that I didn't recognise at the time. I felt nauseous when I smelled certain cleaning products or hand sanitisers that reminded me of the hospital. I'd get carsick every time we drove near to the route that took me to hospital. It was only when I discovered my mum's journals from the time that I pieced this together. Once I realised that the nausea I was feeling was psychosomatic, I never experienced it again.

Rosie running the 2025 London Marathon

What life looks like now

These days, I'm perfectly healthy. Thankfully, I've had no long-term effects from chemo, and I hardly ever think about it. I moved to the UK to do my undergraduate degree at Oxford University in 2012 and have been here ever since. I have wonderful friends and family both here and back in Sydney, and a great job working in languages and technology. I'm privileged enough to be able to take multiple international trips every year. I'm now in my early 30s, as my parents were when I was diagnosed.

Giving back

Earlier this year, I raised money for CCLG by running the London Marathon. I started jogging with Mum before school when I was 13 and have been doing it ever since, so it was maybe inevitable that one day I'd attempt my first full marathon. I knew I wanted to do it for a good cause, to do something to give back to an organisation like those that supported me and my family when I was sick. Thanks to developments in cancer research by charities like CCLG, the survival rate for ALL in children under five is now 90%.

I know I was incredibly lucky. Some children and their families have it much harder. I never want to run a marathon again (people who do this more than once are crazy!), but it feels great to know I can. My life isn't always perfect, but my problems these days are those of a typical 30-year-old woman – will my landlord ever repair my floorboards, and will any man ever live up to the expectations of my fictional heroes? The answer to both is probably not. But it's a life I'm grateful to have – and the way cancer research is heading, it's a life I hope a lot of other kids will get to experience, too.

▲ Graduating at Oxford

The future of children and young people's cancer research

Ashley Ball-Gamble

*Earlier this year, CCLG launched its new research strategy. **Ashley Ball-Gamble**, CEO of CCLG, explains what this means for children and young people's cancer.*

When CCLG (then known as the UK Childhood Cancer Studies Group) was founded back in 1977, the goal of its members was simple: to make things better for children with cancer. At the time, fewer than three in 10 children survived their diagnosis, and there was very little research happening in childhood cancer. So, a group of professionals came together to launch clinical trials, collect vital data, and create a supportive community to drive change.

Fast forward to today, and thanks to decades of research around the world, more than 80% of children now survive cancer. But there's much more still to be done – I want everyone to not only survive but thrive after their cancer. Children and young people deserve a life free from the long-term effects of treatment that are still all too common. That's why funding research is so important to us.

Earlier this year, we changed our name to CCLG: The Children & Young People's Cancer Association. It's a name that better reflects our commitment to teenagers and young adults as well as younger children. That change gave us the chance to pause and reflect on what really matters to us as a charity – which led to our innovative new research strategy.

Our new research strategy

We know that making meaningful progress in children and young people's cancer research isn't only about handing out grants. So, this strategy isn't just about what we fund – it's about how we support the whole research community to work better together, listen more closely to lived experience, and drive lasting change. We have focused on developing four key areas to ensure everything we do contributes to a brighter future for children and young people with cancer...

1. A coordinated, collaborative approach to children and young people's cancer research

We believe no single charity, hospital or research institute has all the answers. By leading coordination efforts and working together, we'll ensure that the right research priorities are identified, the highest quality research is funded, and no resources are wasted.

2. Funding the best research, led by the best minds

We're committed to funding research that drives meaningful progress in the treatment, care, experience and outcomes for children and young people with cancer. By focusing on the areas where we can have the biggest impact, we'll ensure every pound we spend works harder for our community.

3. Lived experience is at the heart of children and young people's cancer research

The voices of those with lived experience (those who have had cancer as a child or young person, and their families) are essential to driving children and young people's cancer research that truly makes a difference. By placing lived experience at the heart of everything we do, we ensure our research addresses real-world priorities, delivers meaningful outcomes, and empowers researchers and families.

4. A thriving children and young people's cancer research community

Research is a continuous, long-term process, where incremental advancements over time lead to transformative outcomes. To sustain this, we need a research community that attracts talent, nurtures growth, provides opportunities for a wide range of people to get involved, and ensures researchers can thrive.

How this all will help

With CCLG acting not just as a funder of research, but building collaborations and championing this field, we aim to drive bigger, bolder and faster change. That means helping researchers develop their ideas, giving them the support they need to grow, and making sure research is more joined-up, inclusive and impactful than ever before.

We want a future where every one of the top research priorities – identified by patients, families and professionals through the James Lind Alliance – has been addressed. Where every child or young person not only receives the best treatment, but also has a better experience of care. This strategy is a step towards that future.

A parent's view...

The hope of making memories during palliative care

Vicky Robayna's daughter, **Liz**, sadly died from a rare form of cancer aged 17. Vicky explains how, with the right support, there's hope for families that their child can be comfortable during palliative care, allowing them to make memories and embrace life in the time they have.

Liz with her brother, Mateo, Vicky, and her dad, Aaron

When we first saw the word 'palliative' written, our hearts sank. Diagnosed with desmoplastic small round cell tumour (DSRCT) – a cancer with less than a 15% five-year survival rate – we knew Liz's chances of survival were tiny, but reading those words felt as though everyone had given up.

We weren't ready to accept that Liz would die. Instead, we scoured the internet looking for cures, desperate to find anything that might save her. Liz was more pragmatic. Unlike us, she didn't complain. She simply set about living her life.

In the 10 months that followed, Liz taught us that palliative care can be about living not dying. She went on three Disney cruises and a trip to Disneyland Paris. She rode rollercoasters at Alton Towers and LEGOLAND Windsor. And she took photographs that appeared in national and international media publications.

Liz never shied away from the truth. She always knew she would die. Thankfully, she was blessed with a medical team who championed her desire to live. Her team in Leeds pushed boundaries, allowing her to travel to London to fulfil her photography dreams while on a syringe driver that delivered pain and anti-sickness medications, and working with a team of nurses who delivered her care while she was there. The philosophy of her consultant, Professor Bob Phillips, of 'what's the worst that could happen?' meant others challenged their own preconceptions. Liz was dying. Nothing anyone did would enable her to survive. But what we could do, what we did do, was allow her to truly live her life for as long as she could.

In the 12 weeks leading up to death, Liz was rarely at home. Instead, we made the most of the days we had. Refusing to think of the future, we maximised the present. Liz photographed an investiture at Windsor Castle, which meant she met the Prince and Princess of Wales. She photographed West End actresses and movie stars, drag queens and circus performers, and got to shoot with many incredible photographers.

Liz's photography exhibition

Just one week before she died, Liz had an exhibition of her photographs, held in London – the city she'd dreamed of living in. She bowed out of the world on her terms, with those she loved, talking about her work, not her cancer. It was a night filled with love, talent and admiration. As people left that night, they knew they wouldn't see Liz again. It was, in many ways, a living funeral without the tears. Words weren't needed, the fact that people had travelled from all over at only a couple of weeks' notice said it all. Liz knew how loved she was. Those she invited knew they were her people. It was a guest list curated by her. She was in control of the last act of her life.

In the week that followed, Liz became increasingly tired, but even then, she didn't stop living. There were photographs to take, sweet shops to visit and family to love. Her final night was spent watching her nine-year-old brother, Mateo, swim for his swimming squad session. She smiled in pride, managing to stay awake for the whole hour. Liz went to bed that night falling asleep for the final time, leaving him in no doubt she 'loved him most'.

Liz was young, she was alive, she was determined. She challenged all our preconceptions, determined that her life would be about living not dying. Liz left us, her family, with a bank of memories that will sustain us for a lifetime. And she left the world the gift of remembering to make the most of life.

See Liz's photography on Instagram **@Lizhatton_photography**
For support for those with **DSRCT see @CaptureDSRCTC**

Why does neurodegeneration occur in Langerhans cell histiocytosis?

Prof Matthew Collin

- **PROJECT TITLE:** The origin of neurodegneration in Langerhans cell histiocytosis
- **LEAD INVESTIGATOR:** Professor Matthew Collin
- **INSTITUTION:** Newcastle University
- **AWARD:** Approx. £130,000 (funded by CCLG and CCLG Special Named Funds: Jack's Journey, The Isobel Parmenter Memorial Fund, #TeamNimmy and Danny's Dandelion Appeal)

A small number of patients with Langerhans cell histiocytosis (LCH) may develop a difficult-to-treat condition called neurodegeneration, where their nerve cells slowly stop working and die. It typically affects the brain causing clumsy movements, unsteadiness and slurred speech. Parents and carers may also notice more difficult behaviour or slower progress at school. This problem is only seen in about 10% of patients where LCH is found in two or more organs or body systems, known as multi-system LCH. Even the newest drugs like vemurafenib and dabrafenib sometimes produce little effect or none at all. Because it's so difficult to treat, we really need to find out more about the root cause.

LCH is caused by mutations (alterations of the DNA code) in a type of immune cell that usually lives in the tissue, known as a histiocyte, or in more modern terminology, a macrophage. Some of our macrophages are formed in the first few weeks of life, developing from a primitive blood stem cell and migrating all over the body, even before there's a blood supply. As the organs grow, other macrophages arrive from the blood. In the end, we have a mixture of primitive and blood-derived macrophages.

The key question is when did the mutation occur in LCH? If it occurred in the first few weeks of life, which we know is possible from other childhood cancers, then it could have got into the primitive macrophages and sneaked into the developing brain like a kind of 'sleeper agent'. If it occurred later, with the formation of blood cells, then it might be an 'insurgent' that got into the brain at the time that LCH is causing illness all over the body. If we can decide between these possibilities, we will have the first clue about how to prevent neurodegeneration in a logical way.

Our research

The research programme funded by CCLG is a collaboration between blood cancer doctors and scientists at Newcastle University (myself and Paul Milne) and the Wellcome Trust Sanger Institute (Jyoti Nangalia and Kudzai Nyamondo). Using blood stem cells from children with multi-system LCH, we're making a 'phylogenetic map' of single cells, which is like a family tree that shows how all the cells are related to each other. Some cells will contain the mutation driving LCH (BRAFV600E), and the map of all the cells will tell when that mutation occurred. If we track it to very early life, then it's possible it entered the brain inside the primitive macrophages. If it appears later, then it must have been the blood-derived cells.

We've analysed three patients with LCH aged between one and five years old. We're at the stage of sequencing single cells of their blood to construct their phylogenetic maps. We've successfully completed this step for three adults with histiocytosis in a parallel research project, but the children are proving a little more difficult and we've had to adapt some of our methods. We expect to have results towards the end of 2025.

Neurodegeneration can be a very difficult problem to deal with for patients and their families, for many reasons. Understanding it has been a very tough nut to crack partly because it's, mercifully, relatively rare. We really hope that this new approach will allow us to go back in time to find out the root cause. This can only help with developing much-needed treatment approaches. We're very grateful to CCLG and its supporters who have committed this funding to the project and hope to bring you our findings soon.

60 SECONDS WITH

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

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

A: I studied medicine at Clare College, Cambridge, then Somerville College, Oxford, before doing my 'house jobs' around Oxfordshire. After then getting on a paediatric rotation, I ended up in oncology as my first job in paediatrics. I immediately felt at home with the mixture of doing, using and developing research along with developing such meaningful relationships with the patients and families. I then moved back up north to do my registrar jobs, and through this time had a keen interest in getting evidence used in practice. At the end of my training, I took a consultant role part time and did my PhD, and now I'm a professor.

For the past 18 months I've been the Director of the Candlelighters Supportive Care Research Centre in York, which has allowed us to develop, bring together and advance many new projects in supportive care. Supportive care is, essentially, all the stuff that isn't frontline treatment. We've fostered new collaborations with some very different research teams to look at properly addressing many of the side effects, and unpleasant elements, of the therapies we need to give. At the moment, we're looking at trying to keep improving treatment for febrile neutropenia, which is a serious complication in cancer patients where they have a fever when there are very few infection-fighting white blood cells called neutrophils. We are also getting people in the UK to be able to use a light treatment called photobiomodulation to treat mucositis, an oral side effect of chemotherapy, and we're creating more high-quality supportive care guidelines.

Q: How does your research offer hope for children and young people with cancer?

A: We know that by conducting research we can advance care. Hopefully, our research means we can prevent or manage side effects, including potentially fatal side effects, saving lives and making the experience of treatment more tolerable. That in itself might mean the longer-term effects are reduced, too.

> "Tell us what research is needed and take every opportunity to feedback on your good and bad experiences."

Q: What does your job mean to you?

A: My job can involve reviewing which treatments should be used, teaching research methods, input on clinical studies, chatting with families about their therapy or scans, or making sure our medical school can train academics effectively. The job that I have gives me a chance to do things in the world that matter; to bring my talents to make the world (a tiny) bit better.

Q: What's the most rewarding thing about your job?

A: Seeing people live their lives fully and tremendously – patients, families and staff.

Q: What developments excite you in children and young people's cancer treatment and care?

A: Loads of things! Different treatments, more accessible data, more trials with better ways of managing adverse effects, clearer ways of making decisions in treatment and beyond, more involvement of patients and families in making research happen, and the possibility of fewer children being stuck in hospital and suffering the effects of cancer and the therapies used to treat them.

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

A: Tell us what research is needed and take every opportunity to feedback on your good and bad experiences. We know that cancer, its treatments and effects are horrible, and we want to improve outcomes for all.

ASK THE

Expert

Jennifer Laidler, University of Birmingham's Cancer Research UK Clinical Trials Unit

What are **clinical trials** and why are they important?

Clinical trials play a crucial role in improving clinical practice and outcomes for children with cancer. They offer a way to test promising new treatments in patients in a controlled and safe manner. This advances clinical understanding and allows children to benefit from the latest medical advancements, tailored to their unique developmental stages and needs. The University of Birmingham Cancer Research Clinical Trials Unit is a global leader in running clinical trials and is responsible for most academic-led children's cancer trials in the UK.

How do they work?

To discover and test any new cutting-edge treatments, clinical trials are important to show if they're effective and whether they cause any side effects. When investigating treatments for children's cancer, it's important to note that children aren't simply 'small adults', and their bodies can react differently and require specific research to determine appropriate dosages and treatments. Clinical trials for children's cancers could be used to test treatments which have previously been found to be effective in adult cancers, or they may be entirely new treatments.

A clinical trial may compare two or more different treatments to see which is more effective or causes less side effects, or it may compare different doses of a treatment to identify the appropriate amount to give while balancing efficacy and side effects. After enough patients have been recruited and treated in the clinical trial, the data will be analysed, and a report will be published showing the results of the trial. The treatment may then be considered if it needs further investigation or it should be recommended as a 'standard' treatment in the future.

Who's eligible?

In order to ensure that the results of a trial are reliable, the patients who are recruited are selected according to a list of 'eligibility criteria', which may include the type of cancer, previous treatments received, and a check that the patient is well enough to have the treatment. In clinical trials for those types of children's cancers which are very rare, trials often recruit patients from multiple countries to obtain enough data to effectively assess the treatments.

How does consent work?

The decision to take part in a clinical trial requires discussion between the patient, their carers, and their medical team. The clinical trial may require additional visits to the hospital and the treatments and tests may involve a risk of additional side effects. These are described in a patient information sheet and the patient and their carers can take time to ask questions and consider whether to enrol in the trial. In clinical trials for children, the patients may be too young to be able to make the decision themselves. In this case, age-appropriate patient information sheets can be provided, and the patient's carers must decide on their behalf.

After being informed of the potential benefits and risks of taking part, the patient and their carers must sign to confirm that they understand what the trial involves and that they agree to take part in the clinical trial ('informed consent'). This is entirely optional, and the patient can decide to come off the clinical trial at any point without explaining why and without their care being affected.

Do you have a question to ask one of our experts?

Please get in touch by emailing **info@cclg.org.uk** or via DM on our social channels. We may feature your question on a future 'Ask the Expert' page to help other families and patients who have the same question.

Take part in CCLG's £600 in 6 months challenge...

Can you raise £600 in 6 months to fund life-saving cancer research for children and young people?

Whether you run, walk, cycle, swim, bake, or hold a quiz, it's completely up to you. Simply sign up online to register for your **free fundraising pack.**

Scan the QR code or find out more at https://bit.ly/4oa7kIN

CCLG The Children & Young People's Cancer Association

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