

ANTHONY  
NOLAN

saving the lives  
of people with  
blood cancer

# Unlocking new ways to treat every patient

**Our  
Organisational  
Strategy**

2023-2028



## Introduction

**We are Anthony Nolan. We are pioneers in transforming the lives of those needing stem cell transplants across the globe. And we have always believed new ways to save and improve lives can and must be found.**

We have half a century of experience and expertise in matching patients to donors, saving lives and transforming futures for patients. And we're still learning, still growing and still pushing the boundaries of what transplants and new cell therapies can achieve. We know there is so much more that can be done and we're ambitious about doing it. So our strategy is ambitious too. We want to be sure that background, ethnicity or circumstance stops no one from having the best possible treatment and support. We want new therapies to be developed and available for patients more quickly. And we want every patient to enjoy a good quality and length of life after their treatment. Over the next five years we're determined to embrace the opportunities and innovations that we know will improve outcomes for so many more patients. Because they need and deserve nothing less. And because it's what we do.

A word from our CEO Henny Braund

**I'm delighted to share our new five-year strategy with you. At its core, it's about using our experience and expertise to unlock the exciting new treatments we know will save and transform the lives of every patient who needs us.**

I'm so proud of all we've achieved over the past 50 years, but we need to do even more. Because we know not everyone who needs a transplant can access one, and not everyone who has a transplant survives. And we know that simply surviving is not the same thing as thriving.

Which is why we're seizing the opportunity to do more. Right now, healthcare is changing at pace, and scientific research into new cell therapies promises to inform – and transform – the ways in which we treat blood cancer and blood disorders. It's an exciting time and we're forging ahead, bringing hope to more and more patients. Our teams are as determined as Shirley Nolan was in 1974, when she founded the register to find a match for her young son. And our focus has never wavered.

We're deeply committed to the patient of today and the patient of tomorrow. As we move forward with our strategy, we're able to draw on 50 years of research, innovation, and expertise to make things happen. And our knowledge fuels our ambition. By bringing together our scientists and our patients, our clinicians and our researchers, our data insights and our donors, we will transform the future for more patients. We will achieve the most we possibly can for everyone who needs us.

We'd love to have you with us for the journey.



**Henny Braund**  
Chief Executive



**In 1974 Shirley Nolan's little boy Anthony was born with a rare blood disorder and the only cure was a bone marrow transplant.** None of his family were a match, and none could be found. He sadly died at the age of seven leaving Shirley not only devastated but also determined that no other family should have to go through the same. She established the world's first stem cell register and the legacy of her pioneering spirit is what still drives us today. Shirley started something incredible and we have a duty to continue it.

## Our vision and purpose

### OUR VISION

## A future where every patient who needs us can survive and thrive

At Anthony Nolan everything we do is for our patients. Those we are working with for the long-term, striving to ensure they find a brighter, better future. Those we've only just met, who are dealing with shock and waiting to hear what happens next. And those we haven't met yet. Those who'll need us tomorrow. Next month. Next year. While we plan our direction and focus for the next five years, they are always at the forefront of our minds and the passion we all share to do the best we can for them is what inspires our vision and gives us our purpose.



### OUR PURPOSE

Uniting people and science to unlock the cures, treatments and transplants that will transform the future for more patients



## Our aims...

**We are excited about what the future holds – for our work, and for every patient who needs a stem cell transplant or cell therapy. We have come so far, and achieved so much, but we need to do more and do better for our patients. We have to tackle the challenges they continue to face and we have a wealth of opportunities available to help us do it.**

Over the next five years we will focus particularly on the three areas of our work where we think we can have the greatest impact, and make the biggest difference for the most people.

### **Aim 1: Survival**

To give every transplant patient the best chance – and quality – of life.

### **Aim 2: Equity**

To ensure all patients have the best access to, experience of and outcome from, treatment.

### **Aim 3: Progress**

To explore and embrace new cell therapies and make them available for patients more quickly.

## ...and how we'll achieve them

**In order to be successful in these ambitions we'll be using our three most powerful tools to approach each of these aims – Discovery, Data and Donors.**

### **Discovery**

Our pioneering research helps us push boundaries as it provides the evidence we need to better understand the world of stem cell transplantation, and influence for change.

**“** *Anthony Nolan's Patient/Donor project has changed practice in the field of unrelated donor haematopoietic cell transplantation, and in the field of Histocompatibility and Immunogenetics, both in the UK and worldwide. From our early work on the importance and impact of HLA-DPB1 when matching patients and donors, confirming that the use of younger donors results in better outcomes for patients, and the discovery that ultra-high resolution HLA typing, made possible by next generation sequencing technologies, improved survival and lowered the risk of GvHD, we have been working towards translational research that has real world impact for patients. But we don't plan to stop there – our future work will continue to identify factors that lead to better matches and improved outcomes for all patients.* **”**

**Dr Neema Mayor, Head of Immunogenetics Research at Anthony Nolan**



## Data

Understanding the rich data we gather gives us the insight into each individual patient's unique needs so we can focus our decisions, efforts and resources to meet them.

**“** *There is emerging evidence that socioeconomic status may influence stem cell transplant outcomes including survival, morbidity and quality of life. However, at the moment in the UK there is no widely accepted method of routinely collecting information about socioeconomic status or quality of life post-transplant. The patient services team have identified this as an area of opportunity and are developing a portfolio of social and behavioural science research to gather patient-reported outcome data.*

**Dr Gemma Pugh, Research Lead – Patient Services**

## Donors

Anthony Nolan's work simply wouldn't be possible without the incredible people who donate their cells and cord blood for research or transplant. It is their selfless generosity that saves three lives a day.

For 50 years our donors have been giving their cells to patients in need and had a direct and immediate impact on saving lives. This will remain core to what Anthony Nolan does and achieves, but there's a growing opportunity for donors to make a difference in new ways too. By contributing their cells to research and development of new treatments they will be helping us take monumental strides and potentially reach even more patients dealing with a range of conditions.

**Thanks to our donors, we were able to provide cells for a trial** undertaken by researchers at Great Ormond Street Hospital (GOSH) to treat children seriously ill with leukaemia.

**“** *The trial has shown initial evidence that precise genetic engineering of cells is safe, paving the way for future development of cell therapies for a huge variety of cancers.*

*'The team at GOSH was able to use cells from a healthy donor rather than the patient's own cells, 'tricked' the cells into not attacking themselves and armed them with a receptor that can recognise and attack cancerous cells – all of which will make this treatment safer and cheaper going forward.*

*'We feel excited for patients who may now benefit from precisely engineered cell therapies in the future.'*

**Dr Diana Hernandez, Head of Translational Immunotherapy at the Anthony Nolan Research Institute**

## Our future

**Healthcare is changing rapidly. And our organisation, and our approach, needs to move with it – harnessing opportunities and adapting when necessary. For most patients, stem cell transplants will continue to be the best treatment option. However, transplant is risky and complex and around half of adult transplant patients don't live beyond five years. For those who do survive, their quality of life can be affected by their treatment.**

But scientific research into new cell therapies is developing at unprecedented speed. Meaning we have a huge opportunity to do so much more.

At the same time, inequalities in society mean some people get life-changing treatment and others, depending on their background and circumstances, simply don't have the same experience. This has to change.

These changes have informed, and will continue to inform, our strategy every step of the way. We will bring everything we have learned and achieved to make the most of new opportunities – for patients today and in the future.

## Pushing the boundaries

Our patients are the driving force behind everything we do at Anthony Nolan, but we are led by research. We know that only through expanding our research will we truly create the transformational change we are striving for. An additional strategy document focusing on how we'll use research to remain at the forefront of development and discovery will be available soon.



# 01

## Survival

To give every transplant patient the best chance – and quality – of life

### Our aim:

**More patients will receive a transplant, more patients will survive their transplant and more patients will have a good quality of life afterwards. Focusing on the unique experience of every patient and their disease, provides an opportunity for greater understanding, so their care is personalised and treatment is more tailored to meet their specific needs.**

### Why do we need to do this?

Our register and research have been improving the outcomes and experience of patients for 50 years. But there is still so much more to do. Stem cell transplantation is complex and risky. Currently only around half of adult patients survive beyond five years – and for those who do survive, the physical and psychological effects of treatment can impact their quality of life.

## What will be different in 2028?

- 1 More patients will receive the optimum cells for their treatment in the fastest time possible.
- 2 We will better understand the factors that impact survival rates and quality of life so we can improve both.
- 3 Our research will inform and transform treatment and care, personalising it for every patient.
- 4 All patients will receive the care and support they need to thrive.

### The three ways we'll make this happen...

#### 1 Discovery through research will help us to:

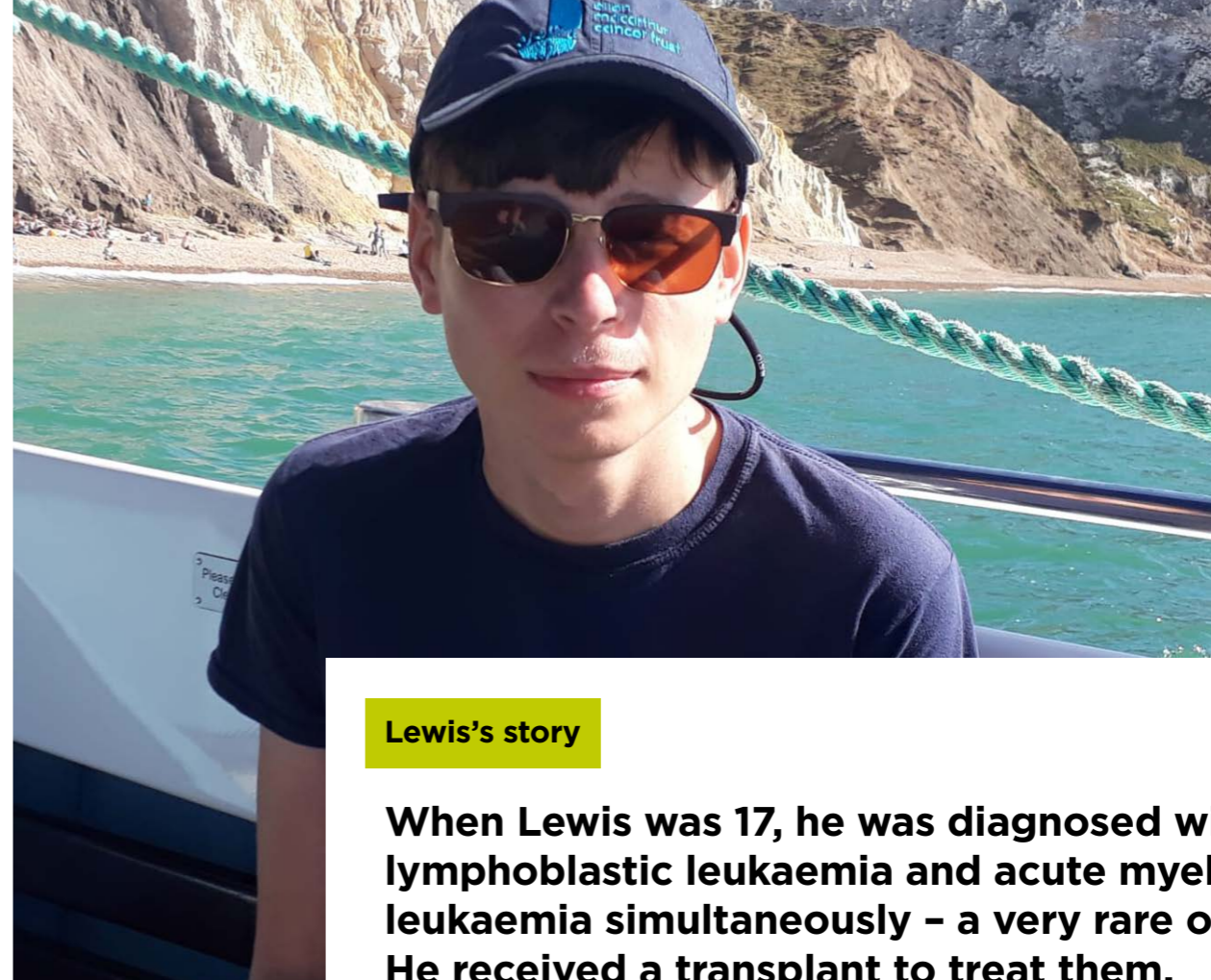
- Better understand the factors influencing survival and quality of life including patient and donor matching.
- Develop more personalised cell treatments in partnership with others.
- Champion research and clinical trials and use our evidence to influence for change.
- Encourage collaboration and development in the international research community.
- Co-create services, treatment and care across the full patient journey.
- Improve healthcare systems and decision-making.

#### 2 Data and the insight it gives us will help us to:

- Create better insights into current and future patient needs and improve the register to reflect them.
- Work with new and existing partners to enhance quality of, and access to, all data for patients, donors and transplants.
- Develop a methodology that allows us to track changes in survival and quality of life over time.
- Explore the role of Artificial Intelligence and machine learning in a clinical setting.

#### 3 Donors and register improvements will help us to:

- Optimise the UK's donor register and cord blood bank.
- Improve the delivery infrastructure so that cells are available in the fastest time possible.
- Improve access to and availability of cells to give patients the best possible outcomes, from both UK and global donor sources.



#### Lewis's story

**When Lewis was 17, he was diagnosed with acute lymphoblastic leukaemia and acute myeloid leukaemia simultaneously – a very rare occurrence. He received a transplant to treat them.**

*'My recovery was arguably the hardest part of my entire journey. So many emotions, a whirlwind, in fact. Anger, anguish, despair, disbelief, to name just a few. For a long time, I was living one day at a time; I wouldn't allow myself to look any further than that. Now I am following my dream studying a Master's in Biomedicine at the University of Reading, following my recent graduation in BSc Microbiology as I pursue a career in biomedical research, with a particular interest in cancer research. My absolute dream is to find a cure.'*



**'There's the psychological impact of you being in hospital and everything that's happening to you and everything that could go wrong, but also coming to terms with what's happened to you.'**

Lewis



### Mary's story

## In 2019, Mary, now 63, had a stem cell transplant after her diagnosis of acute lymphoblastic leukaemia.

*'One day, a lovely nurse came in and said, 'You're next for transplant'. I was surprised because I didn't really know what transplant meant. So, over the next few weeks they explained what it was, what was going to happen and thank goodness they had found a perfect 100% match for me through Anthony Nolan. He was a 19-year-old university student. That's all I know.'*

*'I had my transplant in July 2019. The stay is normally about three weeks. I was in for over six weeks. The cells were starting to take, and everything was looking good, but I was being sick morning, noon and night. I couldn't keep anything down and I became so weak I couldn't even stand. They decided to try one last thing and mixed two different drugs, and within two days I'd stopped being sick.'*

*'It's now been three years since my transplant and things are so different. I'm a Nordic walking leader. I do Tai Chi. I take an Age UK group out for social walks. And now I'm probably more active than I ever was before cancer. It's a much more relaxing life. It's completely different. Going through this has changed the way I look at things.'*



Mary (right) on holiday with her husband post-transplant.



**'It's now been three years since my transplant and things are so different... I'm probably more active than I ever was before cancer. Going through this has changed the way I look at things.'**

Mary, who received a stem cell transplant in 2019



## Equity

To ensure all patients have the best access to, experience of and outcome from, treatment

### Our aim:

**To increase equity so every patient has the best possible access to, experience of and outcome from, treatment. We don't know enough about where, how and why there is inequity. We will find out more about what makes these disparities happen and use this evidence to change systems and remove those barriers.**

**Our recruitment of donors onto the register, as well as our work in nurturing this incredible group of people, will be strengthened to improve outcomes - collaborating with partners in the UK and abroad to find more, better, matches for every patient.**

### Why do we need to do this?

We know some patients find it harder to access treatment and care depending on where they live, their socioeconomic and ethnic background, their education, and their understanding of their health, and the health system. It shouldn't be like this. We need to give every patient the best possible outcome by understanding where, how and why these disparities exist and what we can do to remove them.

## What will be different in 2028?

- 1 More patients will benefit from services that improve their access to, experience of, and outcomes from treatment, care and support.
- 2 More patients from minority ethnic backgrounds will have access to cells and treatment that give the best possible outcome, including from unrelated donors on UK and global registers.
- 3 We'll have gathered more evidence and insight into what causes inequity, and what works to tackle it.

### The three ways we'll make this happen...

#### 1 Discovery through research will help us to:

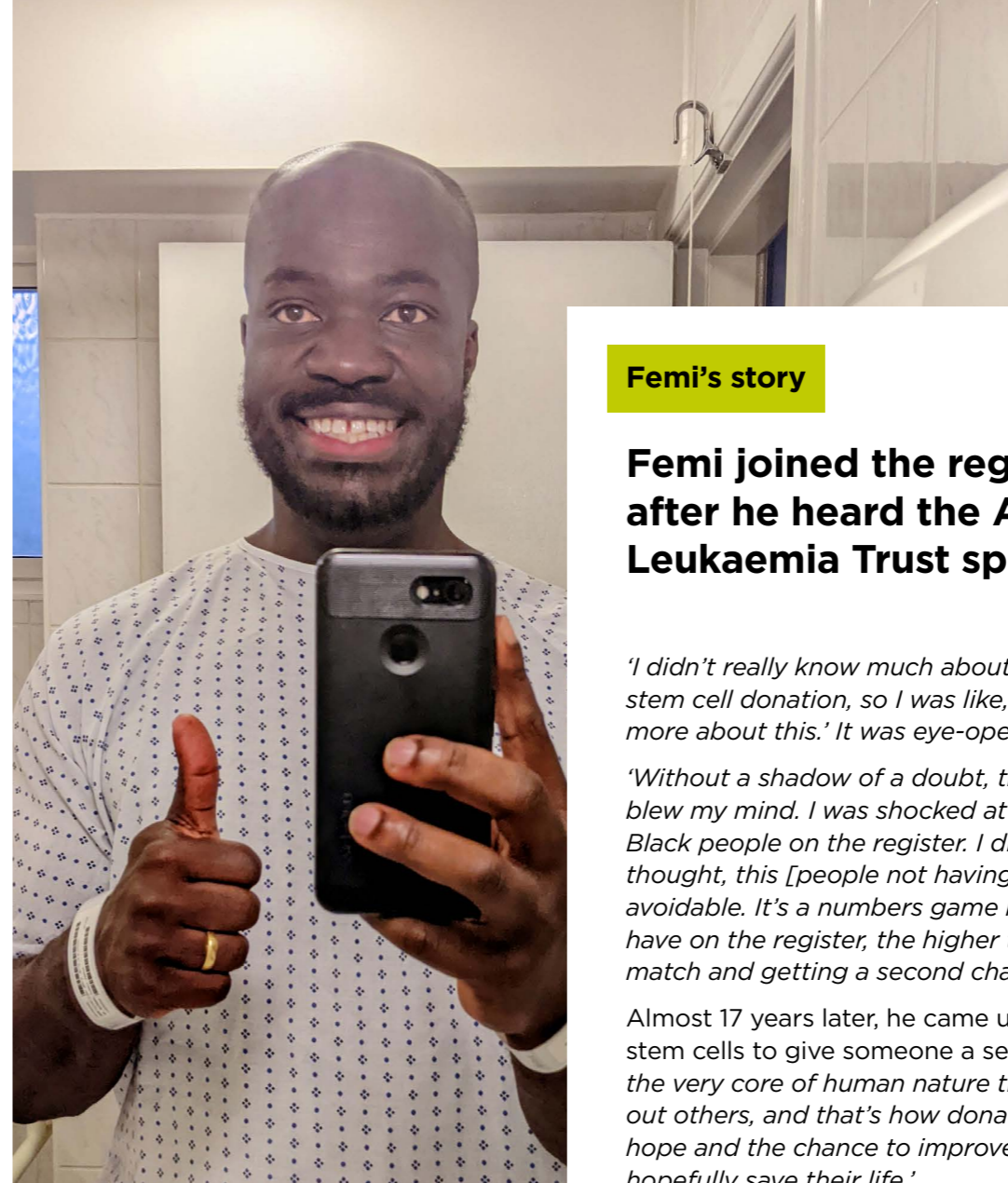
- Understand how and why disparities happen and how they can be tackled, using this knowledge to take action.
- Support the development of new treatments to tackle the effects of a sub-optimal match.
- Understand and remove the barriers to clinical trials faced by people due to background and circumstance.
- Work with patients and clinicians to create services that are equally effective for all.

#### 2 Data and the insight it gives us will help us to:

- Understand how population changes will impact future patient need.
- Use this understanding to improve our donor recruitment, retention and tissue-type matching strategies in line with those changes.
- Work with partners to improve the scale, quality and use of patient and donor data.
- Understand unmet need and use this evidence to understand, and then remove, barriers and disparities.

#### 3 Donors and register improvements will help us to:

- Develop a more diverse donor register, targeting recruitment and retention on under-represented donors.
- Increase availability and use of stem cells from all donor sources, including cord blood.
- Work with registries around the world to improve global availability of and access to donors.
- Improve the technology and infrastructure that facilitate the matching of patients and donors worldwide.



### Femi's story

## Femi joined the register in 2005, after he heard the African Caribbean Leukaemia Trust speak at his university.

*'I didn't really know much about people with blood cancer or stem cell donation, so I was like, 'Okay let's go find out a bit more about this.' It was eye-opening.*

*'Without a shadow of a doubt, the statistics around donation blew my mind. I was shocked at how low the numbers were for Black people on the register. I didn't want to believe it. I just thought, this [people not having a donor] is something that's avoidable. It's a numbers game basically. The more people you have on the register, the higher the chance of someone finding a match and getting a second chance of life.'*

Almost 17 years later, he came up as a match and donated his stem cells to give someone a second chance of life. He says, *'At the very core of human nature there's something about helping out others, and that's how donating felt to me. Donating gives hope and the chance to improve someone's quality of life – and hopefully save their life.'*



**'Without a shadow of a doubt, the statistics around donation blew my mind. I was shocked at how low the numbers were for Black people on the register.'**

Femi

**Zara's story**

**10-year-old Zara had acute myeloid leukaemia, and underwent a stem cell transplant.**

Her mother told us: *'We come from Indian origin, and we knew that it was more difficult to find a match if you're from an ethnic minority background, so we were very worried. We asked our family in India, the US and Canada to start raising awareness and doing events to get people to sign up to the stem cell register.'*

*'Unfortunately, she didn't have a perfect match in the whole world. Then at the end of April 2022, they said they were looking for a cord blood match. In the end, she didn't have a perfect cord match either, but they were happy to go ahead with a 6/8 match. So, she had her transplant on 16 June. Because it was a mismatch, it meant she had a lot of complications afterwards. Now she's home and able to enjoy a bit of normal life again.'*



'We are just so glad that we found a match, even if it was a partial match. Some families don't even have that. I can't even imagine how it would feel when you can't find any match.'

Taruna, Zara's mum



## Progress

To explore and embrace new cell therapies and make them available for patients more quickly

### Our aim:

**We'll develop and push for the approval of new cell therapies that offer an alternative or bridge to transplant in the fastest time possible, making them available to all patients who need them. We'll use our 50 years of experience and expertise, our lifesaving donors, and our pioneering research to help discover new and improved treatments - and ensure they are understood and available for every patient.**

### Why do we need to do this?

Anthony Nolan's purpose is to further improve access to, and outcomes of, transplantation. Alongside this, there are so many emerging new treatments that can help us achieve our aims. By improving the process of getting these new treatments approved and accessible to patients we can make sure they're being used at the scale needed for maximum impact.

## What will be different in 2028?

- 1 More donors will contribute their cells for research into new treatments, and the wellbeing and welfare of those donors will be protected by a robust ethical framework.
- 2 Our expertise, products and services will help drive forward research, development and manufacture of new treatments.
- 3 Every patient's cell therapy treatment, care and support will be shaped by their individual needs and experiences.

## The three ways we'll make this happen...

### 1 Discovery through research will help us to:

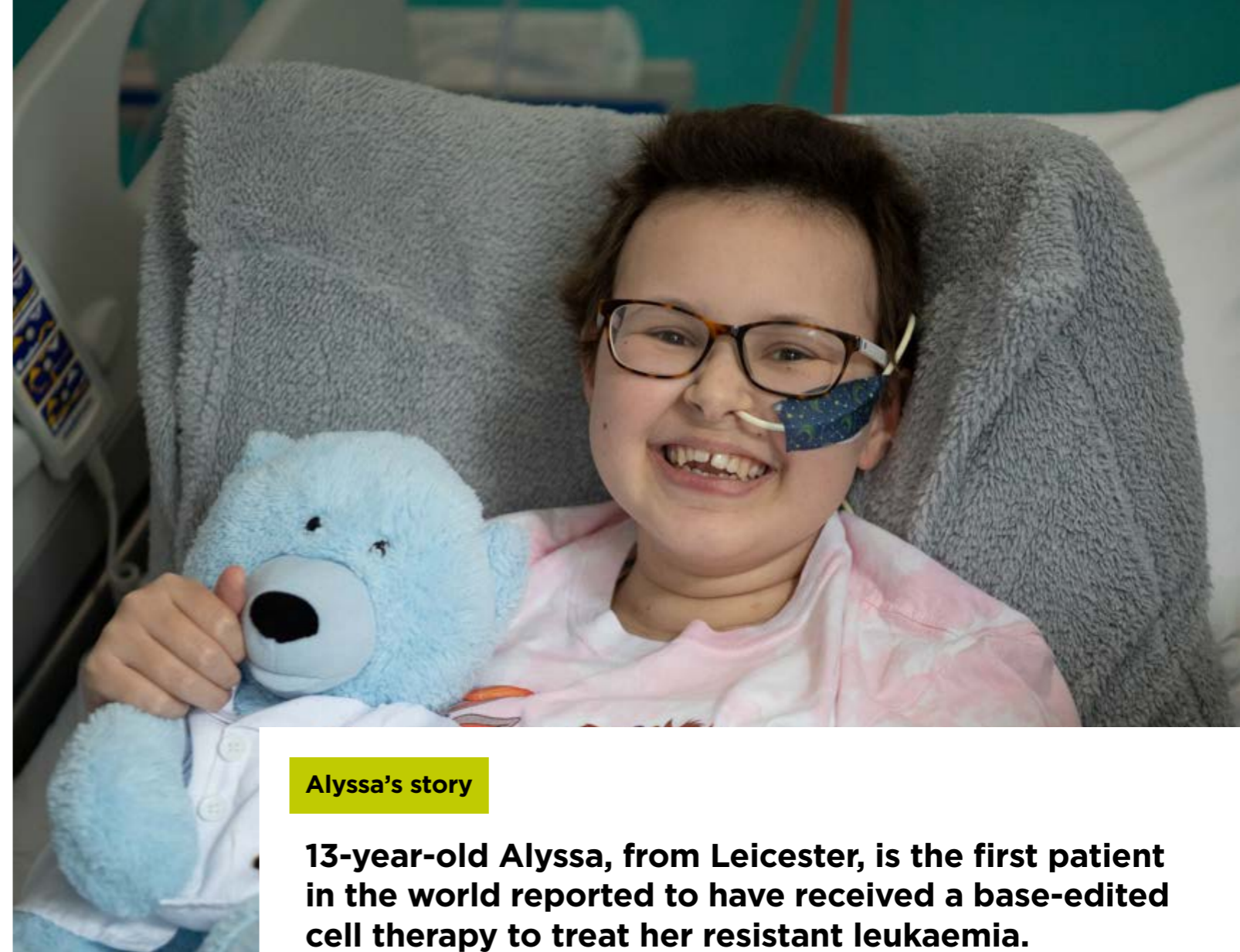
- Use our scientific expertise across bioinformatics, immunogenetics and immunotherapy, coupled with the provision of products and services to contribute to the development of new cell treatments.
- Work with patients and clinicians to develop personalised care pathways for new treatments.
- Provide information and guidance so patients can make informed choices about treatments.
- Identify and dismantle barriers to the research, development, manufacture and adoption of new cell treatments.
- Continue to invest in clinical trials and encouraging diversity in clinical trials participation.

### 2 Data and the insight it gives us will help us to:

- Work across the industry, with the NHS, clinical community and commissioners, to improve the collection, analysis and sharing of data on new cell treatments.
- Use the direct experience of patients to inform this evidence.
- Make the process of sharing this insight into new cell treatments quicker, simpler and more effective.

### 3 Donors and register improvements will help us to:

- Provide high-quality cells from appropriate donors for use in the research and development of new treatments.
- Ensure everyone can trust the ethics, transparency and quality of the process.
- Add to our products and services in support of the development and manufacturing of new treatments.



### Alyssa's story

**13-year-old Alyssa, from Leicester, is the first patient in the world reported to have received a base-edited cell therapy to treat her resistant leukaemia.**

She was diagnosed with T-cell acute lymphoblastic leukaemia in 2021 and went through all the conventional therapies currently available, including chemotherapy and a bone marrow transplant. Unfortunately, her cancer resisted all treatment and came back, with no further treatment options available.

Alyssa was enrolled onto a new clinical trial involving genetically modified CAR T-cells at Great Ormond Street Hospital (GOSH), in collaboration with the UCL Great Ormond Street Institute of Child Health (UCL GOS ICH) to treat her 'incurable' cancer. Just 28 days after receiving the modified T-cells, Alyssa was in remission!

These cells originally came from a volunteer donor who was sourced from the Anthony Nolan register. Now, six months later, Alyssa is doing well at home recovering with her family and continues follow-ups at GOSH. Without this experimental treatment, her only option would have been palliative care.

**Our foundations**

**Anthony Nolan has a proud heritage of pushing boundaries and embracing innovation in order to change lives. And we believe in a future where precise treatments and personalised care for every patient means more people will survive and thrive.**

We'll build on our strong foundations and proud history to achieve our ambitious goals. We'll use what we know, what we have and what drives us to continually move forward over the next five years.

**1 Our patients**

We'll work actively with patients, using their involvement and input to help us better understand and support their needs, and put them at the heart of everything we do.

**2 Our people and culture**

Our people are our greatest asset, so we will invest in them and their development as well as creating a culture where they can reach their potential.

**3 Our diversity and inclusivity**

We need to achieve greater equity, diversity and inclusion, using a range of perspectives and experiences to achieve more for our patients, donors and colleagues.

**4 Our technology and data**

To achieve the most for our patients we'll remain at the cutting edge of the sector by investing in the systems and tools needed to keep growing, innovating, analysing and adapting.

**5 Our resilience and business model**

Having a robust business model allows us to continue generating income that we can reinvest efficiently and sustainably in our work, reinforcing our resilience as an organisation.

**Our vision - and how we'll get there**

Here we've shown how our strategy for the next five years will help us strive towards our vision, through all the resources we have available to us. Building on our strong foundations, we'll use the tools we're equipped with to enable us to fulfil our aims and realise our vision.



**Be part of something amazing**

**This is our strategy for the next five years. But as an organisation we never stand still. We are constantly evolving, reacting and adapting - so our strategy will too. If we need to make changes we're not afraid to do so - not if it means a better outcome and a better future for our patients. Together, we will get there. Together, we'll create change.**

There are so many ways you can be part of our exciting mission and here are three simple ways you can help us save lives straight away:

**1 Join the stem cell register**

Whether you want to donate for someone waiting for a transplant or to help our teams with their pioneering research, you're potentially saving lives the minute you sign up. Join the register [here](#).

**2 Raise funds for Anthony Nolan**

Our journey relies on the generosity of others to help us grow as an organisation, nurture the lifesaving talent we have and keep reaching more patients that need us. To donate visit our [website](#).

**3 Spread the word**

Share this strategy with friends and family, follow us on social media, check out the [website](#) and help us reach more people who share our life-changing vision.

To find out more visit [anthohnolan.org](http://anthohnolan.org)





Thank you for taking  
the time to read our  
Organisational Strategy.



Find out more at [anthonynolan.org](https://www.anthonynolan.org)

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saving the lives  
of people with  
blood cancer