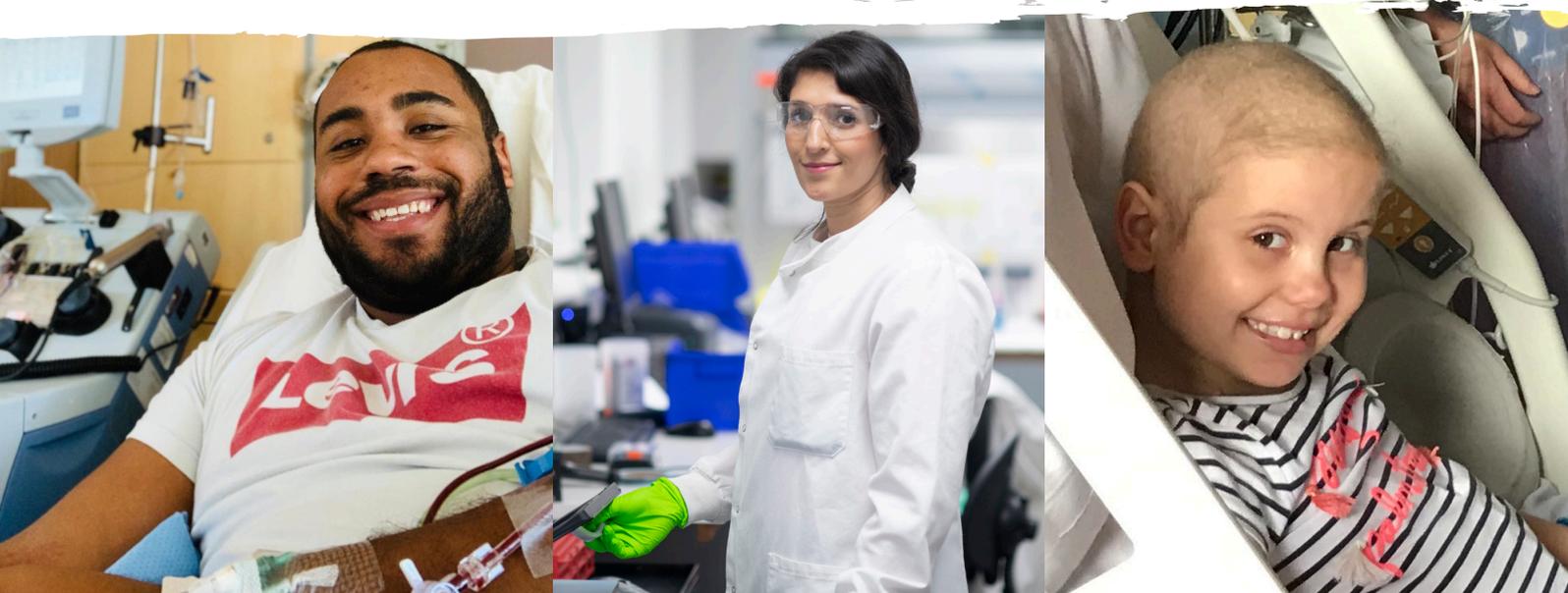


TOGETHER WE'RE MAKING A DIFFERENCE

Our impact in 2019-2020



ANTHONY
NOLAN

saving the lives
of people with
blood cancer

WHAT GETS US OUT OF BED IN THE MORNING?

Whatever our role, we are all motivated by the same thing:
**to save and improve the lives of everyone who needs
a stem cell transplant.**

Every year, 2,300 people with blood cancer and blood disorders in the UK start their urgent search for a matching donor to give them a second chance of life. With your support, we are working tirelessly to find their matching donors, improve their survival chances and support them every step of the way.

WHAT KEEPS US AWAKE AT NIGHT?

There are still people, particularly those from minority ethnic backgrounds, for whom we struggle **to find the best possible matching donor.**

Recruiting the best donors – which means young, male and ethnically diverse – is essential.

Overall, just 50% of adult patients survive the first five years after a transplant, so we've made it a priority to fund and conduct **vital research** which could improve survival rates.

Patients and families don't always receive the physical and psychological help they desperately need. Our **specialised support and campaigning work** to improve access to treatment and care aims to change this.

TOGETHER WE CAN SAVE LIVES

We urgently need to address these issues.

That's why, last year, we launched our ambitious strategy **'Together, We Can Save Lives'** as we aim to harness our position as a donor register, research pioneer, and patient support provider to bring about real, lasting change for patients in survival rates and quality of life.

But, as the name suggests, we really can't do this alone. Saving the lives of people with blood cancer and blood disorders fundamentally relies on our supporters, volunteers, partners and staff all joining forces to take on this vital cause.

WHY

HAVE WE CREATED THIS REPORT?

Here, in our first published impact report, we want to show you how we're progressing towards our aims and what we're proud to have achieved so far. But we also want to talk about where we need to do more, our ambitious future plans, and crucially, where we need your help to make them happen.

By exploring three main areas of our work – [finding matching donors](#), [pioneering research](#) and [patient support](#) – this report is part of an ongoing journey to better define and measure the impact of our lifesaving work*.

Wherever we talk about our activities, impact and numbers, it's from the March 2019 to April 2020 financial year. But as 2020 has been a somewhat unusual year, there are places where we've specifically reflected on the impact of this too.

IF YOU'RE SHORT ON TIME, YOU CAN SKIP TO...

[Our Chief Executive Henny's thoughts on the past year](#)

[How we're busy responding to COVID-19](#)

[The BIG numbers...](#)

[...and how funding made it all happen](#)

[Stories from inspiring \[stem cell donors\]\(#\), \[patients\]\(#\) and \[volunteers\]\(#\)](#)

[Stories from patients who urgently need our help](#)

[A huge thank you to our supporters](#)

[And last, but not at all least, how you can help save lives.](#)

But we're starting with a story that's at the heart of our work – one of two complete strangers meeting in the most remarkable way... 

*You can find a full update on our strategy's progress in our [2019 - 2020 Annual Report](#).

JO

MEETING HER LIFESAVING STRANGER



**'IT'S REALLY SURREAL THAT THE
MAN WHO SAVED MY LIFE IS ON
THE OTHER SIDE OF THAT DOOR...'**

Jo, who met her donor Stefan in 2019 after her lifesaving stem cell transplant in 2012.

'We don't think you'll make it past Christmas' were the words Jo heard in 2010, three years after being diagnosed with Hodgkin lymphoma. Now, a decade later, she's met the donor who gave her a second chance of life. And we caught it all on camera...

OUR STORY IS YOUR STORY

Ever since one little boy and his mother, Anthony and Shirley Nolan, sparked a revolution in creating a register of stem cell donors for people with blood cancer and blood disorders, stories like Jo's have been at the heart of our charity. Stories of perseverance, courage, hope and togetherness – and as Anthony Nolan's Chief Executive, I'm lucky to hear them every day.



WORKING FROM HOME WITH
MY NEW COLLEAGUE, BEAUMONT

Just as facts and stats are key to reporting our impact, so too are our stories. Why? Because by highlighting the experiences of real people, we want to show what our lifesaving work means not just in numbers but in the words of people who have lived it.

That's why, as we reflect on the first year of our 2019-2022 strategy 'Together, We Can Save Lives', you'll find incredible stories of donors, stem cell couriers and inspiring patients like [Jo](#), [Andy](#), [Shahera](#), [Eliana](#), [Grace](#) and [Joel](#).

Of course, the big story of 2020 has been COVID-19, which has presented many unforeseen challenges to us. Our response to the pandemic inevitably demanded an immediate focus on the 'here, now and next'. We've had to react quickly to a fluctuating environment with an uncertain outlook. Globally, COVID-19 has vividly demonstrated the interconnectedness – and in many ways the fragility – of the stem cell supply ecosystem.

To rise to this unprecedented challenge, I'm proud to say our charity has been able to respond with great creativity and innovation, finding new solutions and harnessing technology to enable us to continue our work wherever we are. Every day, we're learning more about our resilience, our impact and how by working together with our supporters and partners, we can do more for our patients.

Far from being a 'once and done' exercise, it's vital that we keep monitoring what's happening, scanning the horizon, and standing ready to adjust our approach when necessary. At the same time, we're looking to the future, asking ourselves how the pandemic could serve as a catalyst for renewal.

We don't yet have all the answers. But nor should we at this stage. We know that our strategy remains sound, and that COVID-19 has brought some of the plans in our pipeline into sharper focus. We need to accelerate and adapt our lifesaving work and lock-in some of the changes we know to be beneficial for patients.

If you're reading this and stories like Shahera's on the following page, then you are part of our journey to save and improve the lives of everyone who needs a stem cell transplant. That makes it not just our or their story, but yours too. Thank you for being a part of it. Together, we can save lives.

Henny Braund
Chief Executive

SHAHERA IS STILL WAITING FOR HER MATCH

**'WE ONLY HAVE MONTHS
TO FIND A MATCHING DONOR.'**

Amina, mum of Shahera, aged 3

'Shahera has been diagnosed with a very rare immunodeficiency disease. She needs a stem cell transplant in the next five years - hopefully next spring or summer. With Shahera's condition, children who were treated when they were older didn't make it. They were very, very sick. So we have months to find a matching donor.'

'Anthony Nolan searched the register - the UK one and the international one - but there isn't a match so with Anthony Nolan's support we've launched an appeal. We want to raise awareness in the Asian, and particularly Bangladeshi, communities.'

'You wouldn't even believe Shahera is ill at the moment. You can't tell. But what's going on inside is a different story. She's not having a great childhood. We want her to be cured so she can have a happy, healthy, long life.'

'It's nerve-wracking and upsetting, waiting to find a donor. It's not easy. We have our bad days as well as good, but all we can do is look forward, and do everything we can to find our daughter a donor.'



RESPONDING TO COVID-19

COVID-19 has had an impact on all our lives, but especially for our patients. When the pandemic began, we knew lifesaving couldn't stand still, so we didn't either:

- **We established an Emergency Handover Hub.** This means international couriers, who are unable to go into hospitals due to quarantine rules, can handover stem cells to one of our UK volunteer couriers for the final lifesaving leg.
- **We kept our Labs and Cell Therapy Centre open.** This was vital to keep transplants moving, including working on the complex process of legal agreements and quality accreditation. In order to cryopreserve donated cells for safe travel on potentially disrupted international journeys.
- **We set up a Telephone Emotional Support service.** Demand for support from our Patient Services team intensified, with patients facing the anxiety of shielding. By collaborating with Work to Wellbeing, we set up an emotional support service to make sure we could be there for them.
- **We made sure the needs of stem cell transplant patients were reflected in national guidance.** Advocating for our patients became even more important as they are part of a vulnerable group needing to shield. We partnered with NHS leaders and senior healthcare professionals across the UK to make sure hospitals have up-to-date guidelines that reflect patients' needs.
- **We focused on finding more donors and keeping them safe.** As we've been unable to hold face-to-face recruitment events, we've driven donor recruitment online to engage with our target young male audience, as well as continue to support patient appeals virtually. We've also provided additional screening to keep our active donors safe as they stopped at nothing to continue donating throughout the lockdown period.
- **We rapidly made our IMPACT clinical trials infrastructure available** to host a Great Ormand Street Hospital study into the effects and treatment of COVID-19 on transplant patients, helping to accelerate nationwide patient recruitment.

While demand for our support and services increased, our fundraising events and income has been severely impacted due to the pandemic. We launched our **Emergency Coronavirus Appeal**, raising £600,000 (as of November 2020), and continue to focus on collaboration, communication and innovation as key for the future. Together, we will get through this.



BRYAN & MONICA

STEPPED UP DURING COVID-19

'THERE ARE FEWER COURIERS AROUND IN THE PANDEMIC SO WE'RE GLAD WE CAN STEP UP.'

Bryan and Monica, who volunteer as part of our team of couriers who transport donated stem cells to waiting patients.

'Our daughter, Helen, had a stem cell transplant in 2014. It saved her life and we wanted to give something back, so became volunteer couriers for Anthony Nolan in 2018 after we'd both retired.'

'If it hadn't been for the transplant Helen had, she wouldn't be here. That's why we're so committed. The need for couriers at the moment is much greater as so many have had to stop [due to being at higher risk of coronavirus]. We thought, "We haven't got health issues, we want to carry on".'

Bryan: *'In some ways, it does feel a bit more scary during the pandemic. We could just lock our doors and stay at home. But there are people going through a horrible time and relying on their transplant, so we're glad we can step up. You feel buoyed up that you can do something for others, especially at this time.'*

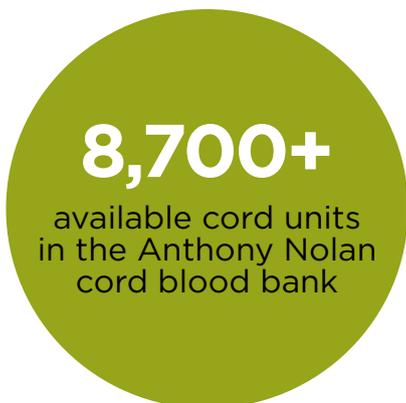
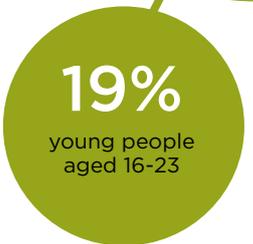
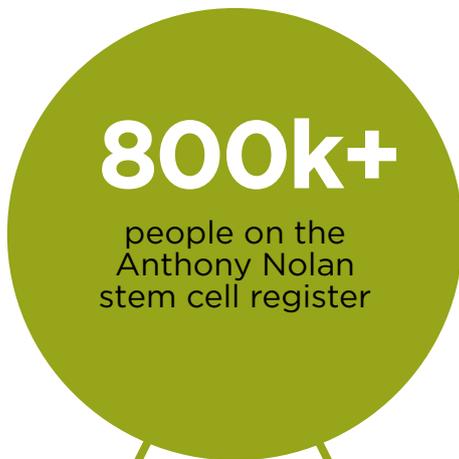
Monica: *'We know what it's like to be sat by a loved one's hospital bedside. These people who are relying on a transplant - their illness isn't suddenly going to go away. They can't wait. So Anthony Nolan's couriers have to carry on.'*



THE BIG NUMBERS 2019-2020



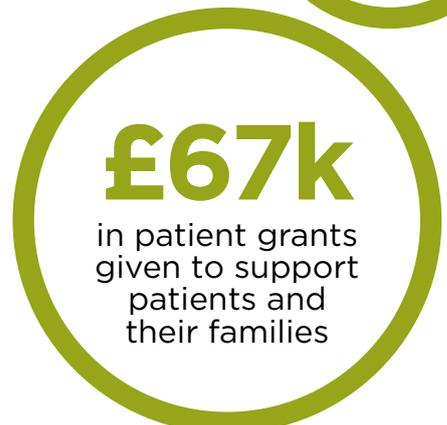
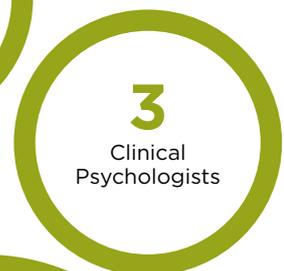
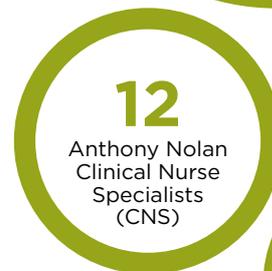
MAKING LIFESAVING MATCHES POSSIBLE



PIONEERING UK-LED RESEARCH



BEING THERE FOR PATIENTS

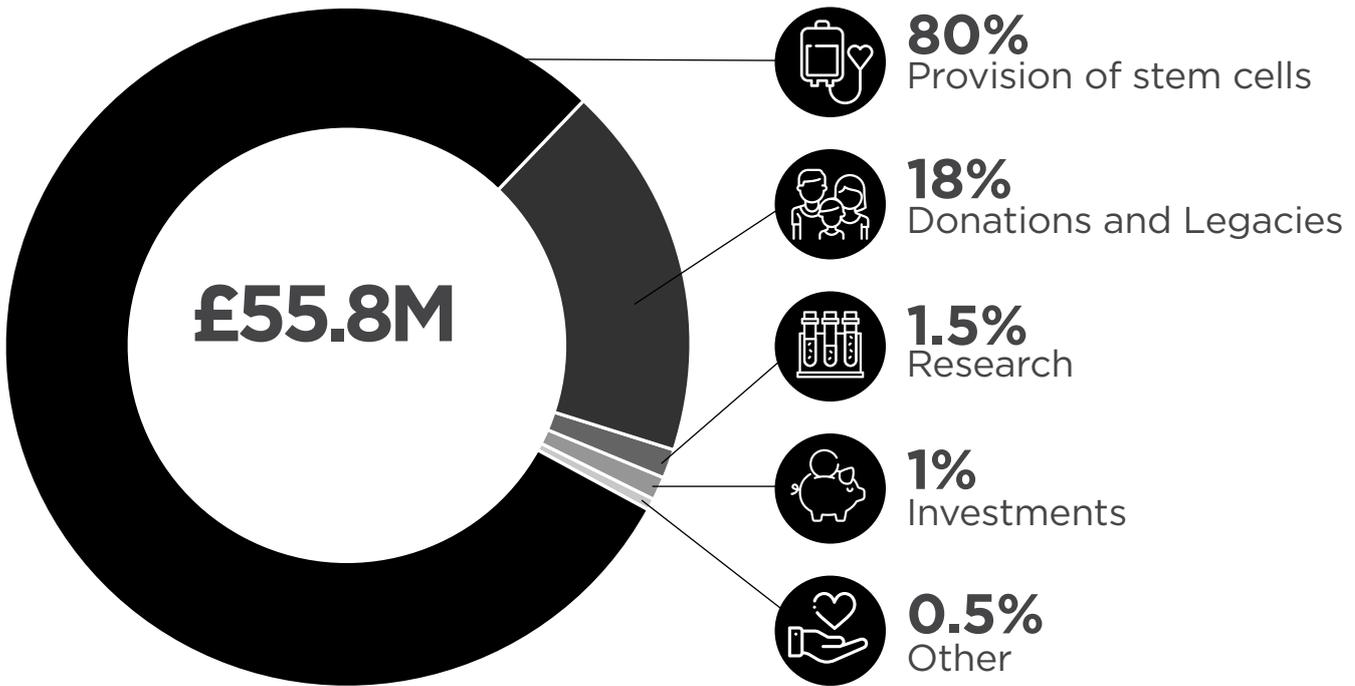


*IMPACT is the clinical trials initiative that we jointly fund

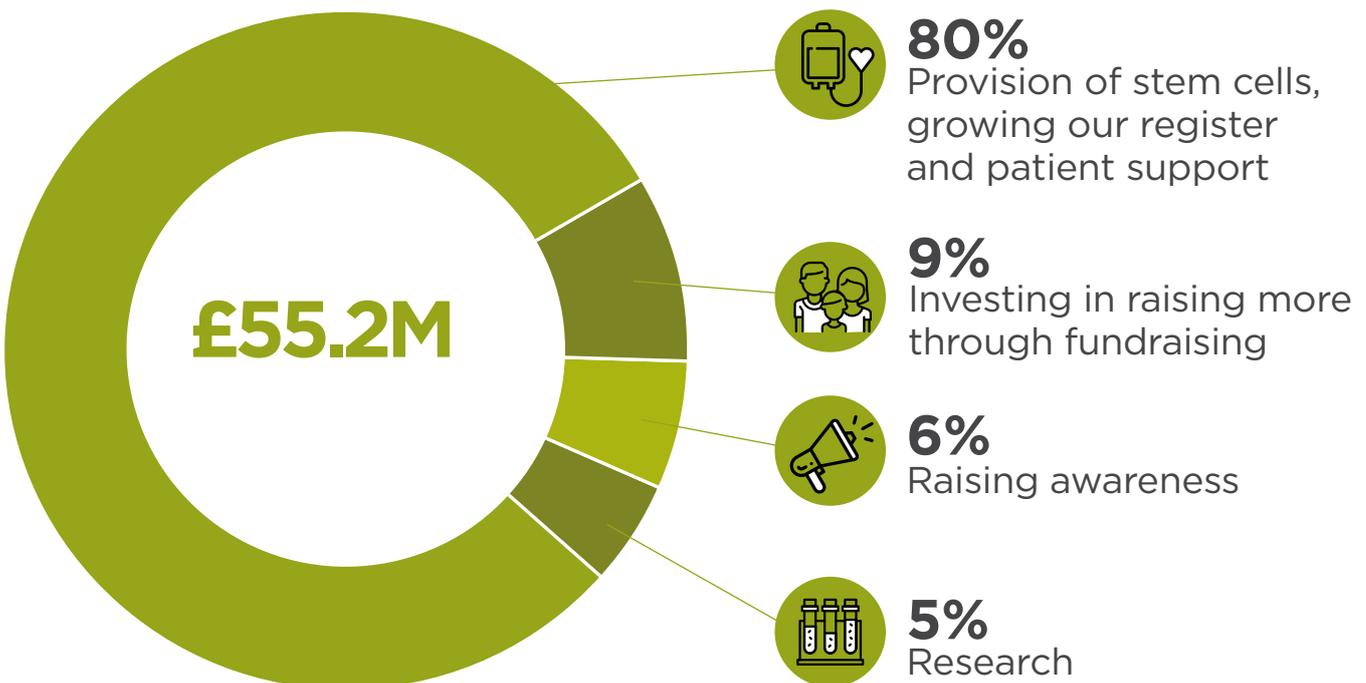
HOW WE FUNDED IT ALL..

These big numbers require generous funding. Here's how we did it:

WHAT WE RECEIVED



WHAT WE HAVE SPENT



MAKING LIFESAVING MATCHES POSSIBLE

WHY THIS MATTERS

Our research shows that given a choice of donors, transplant clinicians will choose a younger, male donor for their patients. **Younger donors are shown to provide better outcomes for patients.** In fact the average age of an Anthony Nolan donor is 26, while male donors aged 16-30 provide over half of all our donations but make up only 18% of our register. It's this information that directly informs our donor recruitment strategy.

But, when it comes to finding the best possible match for patients, there are still **great health inequalities.** We know that despite searching both the UK and international registers, people from a minority ethnic background have a much lower chance of finding a 12/12 matching donor than people from white Northern European backgrounds. Although there are alternative options, such as using cord blood which doesn't need to be matched so closely, we know **there is urgent work to do to dramatically improve this.**

WHAT WE'RE DOING ABOUT IT

We are working alongside our partners to recruit more people onto the stem cell register. We're especially looking for the younger donors who are known to lead to better patient survival rates as well as male donors and people from underrepresented ethnic backgrounds. We're always looking to forge new partnerships to reach these key demographics.

Alongside this, we're championing treatment options such as use of cord blood. Increasing the availability of stem cells from our cord blood programme gives a vital lifeline to patients who are unable to find a stem cell match on the register. We're also thinking globally to help play a key role in working with and developing international stem cell registers and global technology, sharing expertise and collaborating across borders.

THE IMPACT THIS HAS...

'IT HIT ME THAT THIS IS A REAL PERSON, AND I WAS GIVING THEM A SECOND CHANCE OF LIFE.'

Carney, who donated his stem cells in 2019

'I joined the stem cell register at university thanks to Marrow, Anthony Nolan's student network. I saw their posters and thought, "If, God forbid, I needed a transplant, I hope someone out there would be willing to donate." So I signed up in case someone needed me.

'A couple of years later, I was called as a potential match. I was shocked. What are the chances that I'd be a match for a complete stranger, someone I'd never met?! It's amazing.

'During the donation I just kept thinking of the person on the other end, the person who needs me. They must have been through a lot and all I had to do was sit down all day and let the machines do all the work. I felt quite emotional. Somebody was depending on me to get this chance to live.

'I shared my story on social media and so many people messaged asking how they can sign up. It made me realise there's not enough awareness. If I hadn't seen that Anthony Nolan poster at uni, I would have gone about my day and never signed up.'



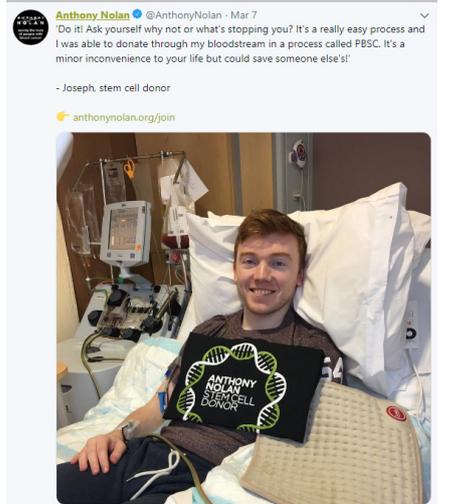
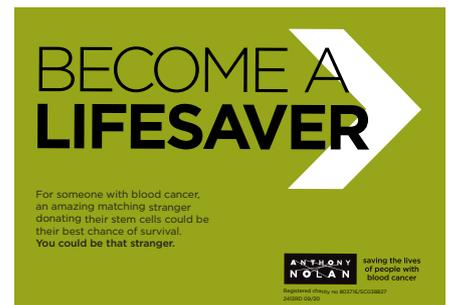
CARNEY, DONATING HIS STEM CELLS

WHAT HAVE WE ACHIEVED SO FAR?

- We grew our stem cell register to 805,504 potential donors by the end of 2019/20, with 66,680 potential donors aged 16-30 added in the last year.
- 12% of our new potential donors recruited have come from minority ethnic backgrounds, following close working with key partners such as African Caribbean Leukaemia Trust (ACLT), investing in online activity to target young male donors, championing patient appeals and delivering targeted recruitment events. While this is broadly reflective of the UK population, it falls short of the ambitious targets we have set ourselves.
- Over 12,400 potential donors from our younger audience were recruited in the last year through activities in schools, including our Hero Project education programme and work carried out by our partners, the Scottish Fire & Rescue Service (SFRS) and the Adrian Sudbury Schools' Education Trust (ASSET).
- Marrow, Anthony Nolan's network of student groups across the country, continues to play a vital role in raising awareness in their universities. Through 49 active Marrow groups, 11,366 potential donors have joined the register at events and online during lockdown.
- We're taking an active role within the World Marrow Donor Association to advocate for registers worldwide, and are working to establish a partnership with the DATRI register in India. We hope this will help patients globally to find a match, including patients in the UK from minority ethnic backgrounds.
- Last year, our cord blood bank grew to 8,723 units which can provide patients with 'off-the-shelf' options to speed up the delivery of lifesaving transplants. In 2019/20 we gave 144 people a second chance of life through the use of cord blood, both in the UK and overseas - 46 of which came from the Anthony Nolan cord bank.

CHALLENGES AHEAD

- COVID-19 has seen huge changes to how we recruit donors, with limited ability to carry out face-to-face events. We need to look at how to rebuild this work with our volunteers and partners to embed joining the stem cell register in communities, support patient appeals, as well as continue to drive focused recruitment online with our target audience of young, male donors.
- Making sure every patient is able to receive the right treatment is a complex issue. To tackle it, we're going to harness our expertise of what constitutes the best match, utilise alternative sources of stem cells for transplantation like our cord blood programme, as well as work in collaboration with our partners, both in the UK and internationally, with the aim of reducing health inequalities.



PIONEERING UK-LEADING RESEARCH

WHY THIS MATTERS

Anthony Nolan is saving lives *right now*. But having more people on the stem cell register isn't the whole story. To give patients the best possible chance of surviving blood cancer and the best quality treatment and care, we also need to drive forward our UK-leading research.

At the Anthony Nolan Research Institute, we're so proud of the impact our pioneering work has on patients' lives. A key example of this is developing our understanding of the importance of donor age and matching CMV* status on patient survival rates, which has improved matching processes. But we know there's still so much more to learn. In the UK, overall, only half of adults, and 76% of children who undergo a stem cell transplant survive beyond five years. Even successful transplants come with years of treatment, debilitating after effects and life-changing implications for patients and their families which our research seeks to improve.

*A common virus that if passed to patients can cause serious side-effects and impact on patient survival rates.

WHAT WE'RE DOING ABOUT IT

We know that research doesn't happen overnight. But we also know it can have the biggest impact on patient survival and wellbeing in the future. Our research continues to investigate three key areas: finding the perfect match for every patient, developing new treatments and cell therapies, and reducing post-transplant complications.

We're also proud to fund and enable research outside of our work, including our Cell & Gene Therapy Services working with global researchers and partners, as well as our joint funding of the IMPACT clinical trials network with Leukaemia UK and NHS Blood and Transplant. This enables transplant centres across the UK to work together to deliver clinical trials focused on stem cell transplantation.

THE IMPACT THIS HAS...

'IF BEING INVOLVED IN A TRIAL HELPS FUTURE PATIENTS, I'M ALL FOR IT.'

Andy, who had a stem cell transplant in 2019 and was involved in an IMPACT trial post-transplant

'I had a stem cell transplant after being diagnosed with leukaemia. My sister was my donor. I didn't realise how lucky I was at the time - I assumed everyone would have a match in their family. So I've learnt that the stem cell register is quite incredible!

'I put my complete trust in everybody who was dealing with me. My consultant, medical team, and everyone at Anthony Nolan were fantastic. So when it was said that I could be put forward for a clinical trial, I put my hand up. If me being involved in this trial helps the medical profession in any way to improve treatment and helps future patients, then I'm all for it.

'The trial was made so simple for me. I had extra bloods and data taken during my post-transplant treatment for extra tests. Everything was explained clearly all the way down the line, especially if I was worried about something. It'll be interesting to hear about the results. Maybe I'll get a wee certificate(!)

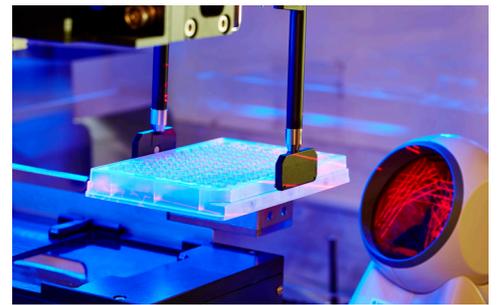
'It's been over a year since I left hospital now and it's been a rollercoaster. My attitude is: if I can do something to help, if they can learn from my experience, that's fantastic.'



ANDY, WHO WAS INVOLVED IN AN IMPACT TRIAL POST-TRANSPLANT

WHAT HAVE WE ACHIEVED SO FAR?

- We're working to improve the outcomes of stem cell transplants through the IMPACT clinical trials partnership. This year, in the fourth and final year of the pilot phase, six clinical trials are now underway. Over the last year we have been investigating extending these trials to paediatric studies, so more children and young people can participate in clinical trials. These findings from which could be used to improve treatment and care.
- Our Patient/Donor project, which has been running for over 20 years, is analysing the progress of over 2,000 transplants to find the genetic factors that are important when looking for a match. This will help us to understand what influences patient outcomes, which we can use to inform donor selection. Already, this has helped highlight the importance of donor age and matching CMV status for patients.
- This research has also influenced our recruitment strategy, as we now look to target younger male donors. Since making this change, the proportion of Anthony Nolan donors selected as a match who are under 30 has increased from 69% in 2016 to 81% in 2020, meaning more patients are getting the best possible match.
- We're providing donated stem cells and other blood products from our cohort of volunteer research donors to researchers around the world who are developing new cellular therapies as part of our Cell and Gene Therapy Services, established in 2019. These 'living drugs' will provide innovative new treatments for patients with a range of conditions, and any funds raised through our service are being reinvested to further our charity's work.
- We're investigating the long-term physical and mental effects of transplant on our patients to understand the range of factors that influence the success of a transplant. This will be used to inform the way we deliver our services and as evidence to influence changes to policy and clinical practice.



CHALLENGES AHEAD

- The COVID-19 pandemic has had an impact on our research and Anthony Nolan was forced to pause some research and furlough a proportion of the research team for a few months. We are therefore currently assessing the full impact of this and re-prioritising as necessary.
- In light of the above, we have not made as much progress in our scientific research over the last 12 months as hoped. However, with the recruitment of Professor Antonio Pagliuca as our new Chief Medical and Scientific Adviser, we're excited to launch our research back into action, and keep working towards Anthony Nolan's lifesaving vision.

BEING THERE FOR PATIENTS NOW & ALWAYS

WHY THIS MATTERS

A stem cell transplant can be a life-changing moment for someone with blood cancer or a blood disorder. But that's just the start of a patient's journey. We passionately believe that it's not enough to save a life - it's also vital to give patients the best possible quality of life, as well as the physical and psychological support they need on the road to recovery.

Physical complications like graft versus host disease (GvHD) can make recovery a long and strenuous process, and patients often need incredibly specific and long-term clinical care and support to manage their wellbeing.

WHAT WE'RE DOING ABOUT IT

Together, our expert patient services team and clinical specialists are guiding patients through every stage of their transplant journey. From helping prepare patients for a transplant, to the transplant day itself and beyond as they recover over time.

Driven by the understanding that every patient is different, we're pushing for more personalised treatments to effectively tailor care and support. As well as campaigning to make patients' voices heard, we're using insight generated from our work to change policy and practice so it benefits patients, both now and in the future.

THE IMPACT THIS HAS...

'WITHOUT PENNY, ELIANA'S ANTHONY NOLAN NURSE, OUR EXPERIENCE COULD HAVE BEEN VERY DIFFERENT.'

Antonia, whose daughter, Eliana, had a stem cell transplant in 2019

'Eliana was only four years old when she was diagnosed with acute myeloid leukaemia (AML). She had her stem cell transplant in 2019. It's the worst thing to be told your child has cancer. I used to catastrophise even once we were back home, so having Penny was amazing.'

'We love Penny. She's Eliana's Anthony Nolan Clinical Nurse Specialist (CNS) at Bristol Children's Hospital. She's just so knowledgeable. You could ask her any question and she wouldn't sugar-coat the answer but would still be calming and reassuring. She'd always keep us informed with any results without me having to ask.'

'She just has a lovely way about her, it was comforting. it's like Penny's part of the family now. She'd even join in on our family Skype calls! Without her, our experience could have been very different. You're not just a number with an Anthony Nolan CNS. You feel safe, and we really need more of them for stem cell transplant patients and their families.'



ELIANA, WITH HER MUM, ANTONIA



ELIANA, IN HOSPITAL



ELIANA, AFTER HER TRANSPLANT

WHAT WE HAVE ACHIEVED SO FAR:

Supporting patients

- Our eight Clinical Nurse Specialists (CNS) and three Clinical Psychologists are helping patients during their transplant journey, providing consistent and holistic support and information to ensure patients and families get the right support at the right time. Four CNS's previously funded by Anthony Nolan have become permanent roles within hospitals, showing how valued they are.
- The Patient Grants Programme has provided £67,186 in grants to patients in 2019/20, an increase of 26% on the previous year, to help with costs related to transplants, including travel to appointments or purchasing household equipment to reduce the risk of infection.

Influencing the bigger picture:

- In May 2019, we published our report [A pathway for post-transplant care](#), developed with an expert steering group consisting of leading healthcare professionals, NHS representatives and patients. This sets out a minimum standard of care and support for transplant patients, for as long as necessary and no matter where they live. We are now focusing on making the pathway a reality.
- We successfully lobbied the government to include stem cell donation in compulsory health education for 11-16 year-olds in England. This is an important move to raise awareness and unlock a new potential audience to join the register in the future.
- We successfully advocated on behalf of patients in two NICE appraisals of new treatments, Letemovir and Treosulfan. We ensured the patient voice was properly represented throughout the appraisal process, while sitting on the decision-making committee.
- We began working with the UK Stem Cell Strategic Forum, with an extended remit to include novel cell therapies, to set up three national working groups to help identify key priorities and recommendations for the next 10 years. This is an opportunity to exchange ideas and expertise with clinicians, industry partners, policymakers and patients to identify any barriers to application and improve outcomes for stem cell transplant patients.



CHALLENGES AHEAD

- This year has seen a series of changes in the political environment with Brexit negotiations and a snap election. We are exploring the opportunities and risks this brings including the longer-term impact of Brexit, and the opportunities of the new government's policy priorities including a renewed focus on research and life sciences.
- The last few months, since the start of the COVID-19 pandemic, have reinforced the importance of our relationships with patients, the transplant community and other health organisations. The delay in treatments and uncertainty that patients have faced means they need us more than ever.

THE BIG QUESTIONS

**After reading all about our key areas of work,
you may well have some questions.**

And we don't want to shy away from those!

So, let's lay it all on the table...

Why do you only recruit people to the register who are under 30?

This is **guided by our research** which shows that, given a choice of donors, transplant teams will choose a younger donor as they provide better survival chances for patients. This is because stem cells from older donors are prone to inflammation and have fewer of the all-important white blood cells patients need to reboot their immune system. As a charity, we need to focus our limited funding and resources on recruiting these best donors.

Once donors are on the register and we've paid to work out their tissue type, they then stay on the register until they're 61. They could be called up as a match at any time, but their lifetime chances of being selected as a donor are higher the younger they join the register.

Why don't you recruit more donors from minority ethnic backgrounds?

This is a key priority to help increase the chances for patients from minority ethnic backgrounds to find matching donors. Currently, patients from a minority ethnic background have a 37% chance of finding an optimal match from an unrelated donor, compared to 71% for patients from a white Northern European background. You can read **Joel's story on page 25** to see the devastating impact this disparity can have.

Although our stem cell register is broadly representative of the UK population, we know people from minority ethnic backgrounds have rarer tissue types meaning we need to urgently make sure they are overrepresented on the stem cell register and continue to grow our cord blood bank.

Lack of awareness is a major issue we need to tackle. The latest stats show our awareness levels at 12.5% amongst people from minority ethnic backgrounds, compared with 55% average for the UK. We're investing in research and working more closely with communities affected to improve these numbers.

We also know we don't yet have all the answers to this, so have formed the Ethnic Diversity Project, a taskforce dedicated to this goal and are working internationally to support registries abroad as well.

How do your Cell & Gene Therapy Services work alongside Anthony Nolan's charitable activities?

For over 45 years, we have signed up potential stem cell donors to our register to help save and improve the lives of people with blood cancer and blood disorders. As this work continues, we are also exploring how we can use our vast experience of transplant services, cord blood donation and pioneering scientific research to aid the development of new treatments. That's why



we've established our Cell & Gene Therapy Services made up of a dedicated team of experts to help provide cell products of the highest quality that can be used by other organisations for medical research. This work would not be possible without the help of our amazing donors who have volunteered to donate their cells for research.

All surplus generated from this service will be reinvested back into the organisation so that we can continue to support patients in need of, and recovering from, a stem cell transplant.

Why do you not have clinical nurse specialists in every transplant centre?

If we had the funding, we would love to have a funded post in every transplant centre. The value they bring is shown by the fact that four of these roles previously funded by Anthony Nolan, are now permanent roles in hospitals funded by the NHS. We're working hard to clearly demonstrate the efficacy of support services and hope to gain the support of commissioners in funding service improvement across the UK.

Why isn't it possible to donate cord blood at more hospitals?

It costs an initial £200,000 just to establish a new cord centre in a hospital on top of ongoing running and staff costs so it's a huge task. The centres we have are in London, Leicester and Manchester as these areas have the most ethnically diverse populations providing more potential matches for patients from minority ethnic backgrounds.

How has COVID-19 impacted your finances?

The impact on finances across the charity sector has been devastating. At Anthony Nolan we're expecting a 13% drop in our income this financial year due to the cancellation/adaptation of many fundraising events and activities as well as a drop in stem cell provisions. In response we launched an emergency fundraising appeal and are looking to diversify our income streams. Although fundamentally our financial health is sound, we now more than ever need vital financial support.

If you've got anymore burning questions, we'd love to hear from you. Head to [anthonynolan.org/contact-us](https://www.anthonynolan.org/contact-us) to ask us anything.



JOEL'S LEGACY

'LET'S MAKE SURE EVERYONE HAS AN OPPORTUNITY TO FIND A MATCH REGARDLESS OF THEIR ETHNICITY.'

Charlotte, whose brother, Joel, died after his stem cell transplant in 2020

'Joel, my brother, was diagnosed with a rare form of leukaemia in 2018, aged just 16. Due to his mixed heritage and complex genetics, it was difficult to find a matching donor for the stem cell transplant that could save his life. Thankfully, his mum was a haploidentical match (half match) and the transplant went ahead. Joel's contagious smile and spirit did not waver, and he was determined to live a normal teenage life. Post-transplant, Joel was in remission.'

'Unfortunately, in January 2020, the leukaemia returned, and in April we were told there could be no further treatment.'

'Even with the diagnosis at such a young age, the pandemic and lockdown, Joel still had the willpower to fight. Sadly, Joel passed away in June, just two weeks before his 18th birthday, but his strength and courage inspired us to continue his fight and advocate his legacy.'

'We're raising awareness of the importance of signing up to the stem cell register, especially for people from ethnically diverse backgrounds. Joel had a much lower chance of finding the best match from an unrelated donor due to his genetic heritage, significantly reducing his chances of survival. With a register of more diverse donors, we can help to address the imbalance and give everybody a fighting chance regardless of their ethnic background.'



JOEL WITH HIS BROTHER, REECE
AND HIS SISTER, CHARLOTTE

ON THE HORIZON

As you can see from this report, there's been good progress, but we have a lot more to do for patients and families like Joel's. We strived to build a strong foundation in the first year of our organisational strategy. Now, we're ready to shift from scoping and planning to delivery and results.

OUR ENDURING VISION

Patients and their families need us now more than ever, and we will continue to ensure this remains at the centre of everything we do. COVID-19 has affected how we work, but not our vision. That remains unchanged.

We must be mindful – and ultimately, kind – when navigating the effects of the pandemic. Our ways of working have drastically changed, but arguably for the better. We have become more flexible with new perspectives which has presented more opportunities for cross-organisational collaboration, working at a different pace, resolutely prioritising, and having a clearer focus to our efforts.

OUR KEY PRIORITIES

Over the next year, we have a number of priorities across the full breadth of our work*. Our focus in the three key areas we've highlighted in this report will be on:



Continuing to **expand and enrich our register**, increasing the information we gather for our new donors joining the register by collecting their CMV status which is increasingly important in finding the best possible match for patients.



With our new Chief Medical and Scientific Adviser, Professor Antonio Pagliuca, who started in late 2020, we'll be **driving forward our research** and continuing to broaden our agenda to understand the range of factors that influence the success of a transplant.



Continuing to provide patients, families and carers with the **support and information** they need through our patient services. With so much uncertainty, we are exploring new and innovative ways to be there for them.

We don't know what's around the corner, but one thing we do know is this: we will not stop.

We will deliver.

For all the amazing people you've met in this report and the thousands you've not, we must work together to help save lives – the partnership on the following page exemplifies just this.

*You can find a full update on our strategy's progress in our [2019 – 2020 Annual Report](#).

SFRS

WORKING TOGETHER, SAVING LIVES

'I'M HUMBLLED BY WHAT THE PARTNERSHIP HAS ACHIEVED IN THE PAST DECADE.'

Ally Boyle, founder of the **Scottish Fire and Rescue Service partnership**, an award-winning collaboration which has seen over 18,000 potential lifesavers added to the Anthony Nolan register through SFRS's work in schools and communities.

'I was diagnosed with myelodysplasia in 2008 and told the only potential cure is a stem cell transplant. This led to me contacting Anthony Nolan and, having worked in the fire brigade for 15 years at that point, I quickly realised that the charity and fire and rescue service have a shared purpose - to save and improve lives.'

'The strap-line for our partnership is 'Working Together, Saving Lives' and that is exactly what we have done. I am humbled by what the partnership has achieved. The vision was always to have a Strategic Partnership that would go beyond recruitment drives in fire stations but what it has evolved into is truly incredible.'

'I FEEL ENORMOUSLY PRIVILEGED TO LEAD THE PARTNERSHIP.'

SFRS Deputy Assistant Chief Officer, **Andy Watt** took over as partnership chair in 2014 after Ally's retirement on medical grounds.

'We marked our tenth anniversary last year and the fact that First Minister, Nicola Sturgeon, sent a message to help us celebrate this moment really showed how much awareness we've raised across Scotland - especially in parliament where we have fantastic support from all political parties.'

'I think it's important to say that not only has this partnership allowed us to increase our ability to save lives, but it has also brought huge benefits to us as an organisation.'



ANDY (LEFT) AND ALLY (RIGHT)

THANK YOU

Everything we've talked about in this report was only possible thanks to our incredible supporters sticking by our lifesaving charity - from the community fundraisers and corporate partners, to dedicated researchers and unstoppable volunteers.

Together we will make sure that more people with blood cancer and blood disorders will not only survive, but thrive.

THANK YOU

We'd like to say an extra special thank you to the organisations and individuals listed here, who are providing outstanding financial support or partnering with us to recruit more lifesaving donors.

1,328 volunteers who supported us, from travelling couriers and passionate school speakers, to all the people who lead community events.

Adrian Sudbury Schools Education Trust	Naomi Ayers
African Caribbean Leukaemia Trust	Niblock Family
The Altendorf Family	Our Henry
All the Friends Groups and Tea Bars of Anthony Nolan	P F Charitable Trust
American Lawyer Media	Police Scotland
Berkeley Assets	RSM
BGC	Runway Run
David and Kathryn Noon	Rik Basra Leukaemia Campaign
David and Ruth Lewis Family Charitable Trust	Sam Safe and friends
Dhiru Shah	Scottish Fire and Rescue Service
Dig Deeper	Shree Kadwa Patidar Samaj (UK)
Miss Elly and Mr Mark Scanlon	The Steel Charitable Trust
Family and friends of Alice Byron	Mr Stephen Allen
Family and friends of Brian Rogers	Mr Stephen Berger
Family and friends of Emma Howie	Team Ed Ammon
Family and friends of Neil McClean	Tom Kopelman
Family and friends of Veer Gudhka	Tracy Sollis Leukaemia Trust
Furniture Village	Trevor Harding
The Garfield Weston Foundation	Turcan Connell
George Spalton	Yates Family Charitable Trust
haysmacintyre	
HelpHollie	
The Jack Petchey Foundation	
James Haycock	
Jamie Wolff	
Julia Lindquist, Nick Ritchie and Paul Lindquist	
Marsh & Parsons	

GRACE

WOULDN'T BE HERE WITHOUT YOUR SUPPORT

**'WITHOUT MY TRANSPLANT,
I WOULDN'T BE HERE.'**

Grace, who had a stem cell transplant in 2016 thanks to donated cord blood.

'I couldn't believe it when I was diagnosed with leukaemia. I asked, 'How? It can't be that!' I was a sports lady, I was healthy. It was really hard.

'I had intensive chemo but it wasn't good enough to cure me. I needed a stem cell transplant to survive. Anthony Nolan tried so hard to find a match for me, but there wasn't one on the register. So they found two cord blood matches. I was so happy. I had my transplant just over four years ago.

*'I'm really thankful for Anthony Nolan. If they didn't exist, I wouldn't have survived. They gave me so much support and encouragement. When I was in hospital I was determined that I would compete in sports again. It was someone at Anthony Nolan who told me about the **British Transplant Games**. I went and I was so happy!*

'Recovery is a long process but I kept walking to keep fit and keep me going. Today I feel very healthy. I still get tired but my friends say, 'Oh Grace, it's like you were never ill.' I'm feeling much stronger. That's why I tell people going through a transplant to keep moving. Keep going. Stay positive. If you give up, it will beat you.

'Without my transplant, I would be dead. I thank God for Anthony Nolan because if they hadn't found my cord blood match, I wouldn't be here.'



GRACE, AFTER HER TRANSPLANT



GRACE, AT THE BRITISH TRANSPLANT GAMES

WITHOUT YOU THERE IS NO CURE

If you've read this far and we're not already talking about how your support can help save lives, we'd love for you to start a conversation at anthonymolan.org/contact-us



saving the lives
of people with
blood cancer