The Anthony Nolan Newsletter for Staff and Volunteers

Issue 21 | Sept 2015

British Transplant Games

Destination: Cure

Immunotherapy

#IGiveASpit

Anthony Nolan
saving the lives of people with blood cancer
Welcome to Insight

Welcome to Insight 21
Every day, Anthony Nolan helps three people get a new chance of life through a stem cell transplant. But what happens after the transplant? Currently, one in three people who receive a transplant don’t survive their first post-transplant year, and 45% of those who do suffer from Graft vs Host Disease (GvHD).

Anthony Nolan’s new organisational strategy sets out how we plan to change that over the next three years, with lots of work already under way to save and improve more lives.

In this edition of Insight, we find out how our pioneering research could lead to new therapies for blood cancer and GvHD. We profile the latest team to get up and running as our ‘SMART Lab’ prepares to adopt Third Generation Sequencing (TGS). We talk to our Director of Operations Nic Alderson about how TGS and other new technologies will lead to faster, more accurate matches – and how we’re already providing fast-track donors.

Plus the latest efforts to raise awareness and recruit more lifesaving donors, and an opportunity for volunteers to have their say and make volunteering at Anthony Nolan even better.

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If you would like to contribute to future issues of Insight, get in touch with internalcomms@anthonynolan.org

Royal Visit

In July, Her Royal Highness The Countess of Wessex visited the Anthony Nolan Cell Therapy Centre in Nottingham to see our Cord Blood Bank’s lifesaving work first hand. Her Royal Highness was welcomed by Simon Dyson MBE, Chairman of Anthony Nolan, Professor Alejandro Madrigal, our Scientific Director, and representatives from Nottingham Trent University. The Countess also met other Anthony Nolan staff at the centre and spoke to patients who had benefitted from a cord transplant. One patient, Sorrel Mason, presented The Countess of Wessex with a posy including daisies, Anthony Nolan’s favourite flower, and helped unveil a commemorative plaque.

Simon Dyson said: “It was an honour to meet The Countess of Wessex and ... I would like to thank her for visiting us and for recognising the importance of the life-saving work by our staff at the centre and beyond.”

Ours Strategy

At a Glance

saving lives: achieving more

Anthony Nolan Organisational Strategy for 2015-2018

Our Vision
To save and improve the lives of everyone who needs a stem cell transplant

Our Approach
Led by science and medical research

Patients
Improving Outcomes and Quality of Life for our Patients

Transplant Community
Leading and Influencing the Global Transplant Community

Excellence
Delivering Excellence, Efficiency and Transparency in our Work

Read the Saving Lives: Achieving More strategy document and speak with your line manager to see how you can help put this strategy into action.
In July, for the first time ever, a group of stem cell recipients came together to form Team Anthony Nolan and compete at the Westfield Health British Transplant Games 2015 in Newcastle Gateshead.

Team Anthony Nolan consisted of nine athletes who took part in 17 events and came back with a whopping 15 medals.

Chiara DeBiase, Head of Patient Experience at Anthony Nolan, said, “We had a fantastic time in Newcastle Gateshead and I want to thank our amazing team, the organisers of the games and all the other competitors who gave us such a warm welcome.

“We were very proud to partner with the British Transplant Games 2015 and it proved to be such a rewarding experience for all concerned. It was fantastic to win so many medals but the real success story from the games was to see everyone celebrating life post-transplant and competing with a smile on their faces. We are already looking forward to next year’s games in Liverpool which I’m sure will be even bigger and better.”

PERSONAL BESTS
To give a taste of what it meant to the Team Anthony Nolan athletes and their families to compete at the Transplant Games, here’s what some of them had to say:

Dr Alex Rowe-Gonzalez, whose 9-year-old son Sam competed in the 5k mini-marathon, said, “Sam had a wonderful time. It has done his confidence the world of good and it was fantastic to see him receive his medal. Sam has missed out on a lot because he has been poorly, and it was truly one of the happiest weekends we’ve had as parents.”

Nadia Stock, who competed in the cycling, swimming, the ‘mini-marathon’ and the 1500m, said, “The games truly are for anyone who has had a transplant, at whatever stage of rehabilitation they are at, and at ages stretching from under 5s to over 70s. The range of abilities was broad to say the least, but that absolutely added to the incredible atmosphere and feeling of all-inclusiveness.”

William Laughton, who competed in the cycling, said, “I would really encourage everyone to take part in the games. There are loads of different sports and activities to take part in to suit everyone. Being part of a team with people that had gone through the same as you is weird, but in a really good way.”

In June, Anthony Nolan launched a brand-new campaign to engage MPs and government ministers following May’s General Election. Destination: Cure maps out a path towards a brighter future for people with blood cancer, outlining the challenges that patients face and what the government should do to help them.

The campaign doesn’t shy away from talking about the difficult challenges that people face. Currently, one in eight people still fail to find the donor they need, and one in three people who receive a transplant don’t survive their first post-transplant year. There will be over 16,000 people living with the long-term effects of a transplant by 2020, and yet many of them will not be guaranteed the care they need to make a full recovery.

Destination: Cure sets out a plan for overcoming these challenges and calls on the government to work in partnership to achieve three bold ambitions: a stem cell donor for every person who needs one, a successful transplant for every patient and the right post-transplant care for every patient.

As with our earlier Save A Life At 16 campaign, the key to success will be to encourage as many MPs as possible to back the campaign and ask government to respond. And, as ever, we can’t do it without our supporters.

When we launched the campaign online, we invited our supporters to fill in a simple form and click a button to email their MP asking them to support the campaign. We were blown away by the response. In the first week, over 5,000 people got in touch with their MP in support of Destination: Cure, and we have fantastic support on social media using #DestinationCure.

On the back of those emails to MPs, we’ve cultivated lots of interest in parliament across the political spectrum, and launched the Destination: Cure report at a successful event hosted by the all-party group on Stem Cell Transplantation in July. As well as supportive parliamentarians, an event was attended by a number of patient supporters who took the opportunity to speak to MPs about their own experiences and why the issues raised in the campaign are important to them.

We’ll be engaging with MPs again at the political party conferences in the autumn to generate even more backing for the campaign, and we’ll be working with some of our closest allies in Westminster to ensure stem cell transplantation remains on the government’s agenda.

To watch the campaign video and support the campaign, go to anthony-nolan.org/destinationcure
IMMUNOTHERAPY

Our Research team is leading the way in new techniques and approaches to restore the delicate balance of the immune system after a transplant – and potentially harness its power to fight cancer directly.

BALANCING ACT

“Immunotherapy is about assisting the natural function of your immune cells to use it as a treatment,” explains Dr Aurore Saudemont, Senior Research Scientist. “Our immune system is actually very good at killing cancerous cells. But cancer is able to evolve and find ways to survive by stopping your immune cells working properly. And sometimes your immune system can become unregulated and start to attack your own cells, which is what happens in Graft vs Host Disease (GVHD) and autoimmune disorders such as diabetes, arthritis and eczema.

“We’re exploring ways of giving the immune system a little bit of a kick or dampening it to restore that balance.”

Our immune systems have two main weapons against cancer: T-cells and Natural Killer (NK) cells. T-cells are part of the adaptive immune system, so they learn to tell the difference between healthy cells that are part of our own bodies (‘self’) and ‘non-self’ cells such as those infected with a virus or cancer. NK cells are part of the innate immune system, and kill anything that looks unhealthy. A third type of cell – regulatory T-cells (Tregs) – regulate the function of the immune system so that it doesn’t attack our own cells.

Cancer cells can evolve to attract Tregs, suppressing your immune system’s ability to attack them. So that’s when your immune system might need a bit of a boost.

NATURAL HELPERS

While some scientists are looking at using drugs to help the immune system – a trial using drugs to stop the blocking effect of Treg cells so that patients’ immune systems can tackle skin cancer hit the headlines recently – our researchers are finding ways to isolate the natural cells and molecules that can do the job for us.

“Because they are naturally occurring cells, they won’t have the same negative effects as some drugs on liver and kidney function,” says Aurore. “We should be able to treat someone with only one infusion of the cells, or maybe two, rather than having to take pills every day.”

PhD student Anna Domogala has been researching the use of NK cells from cord blood to give cancer patients’ immune systems a helping hand. “NK cells in sufficient numbers can overcome the immunosuppressive effects and attack the cancer,” says Anna. “This approach has been tried before, but with limited success, so I’ve reviewed the evidence from previous trials to see what was going wrong and the potential for this to become a successful therapy in future.”

Anna found that a big challenge was growing cells that can survive and multiply enough to do their job once infused into the patient. “In many studies, the cells had been grown in a dish for so long that by the time they were given to the patient they were too ‘old’ to keep dividing much further. But using cord blood cells looks promising. These are obviously very young cells, and I’ve found a technique for isolating them into a product that could continue to proliferate in the patient and mount an attack on the cancer.”

NK cells can also help stem cell transplants succeed by tackling infections while the patient’s immune system is still reconstituting.

STOPPING THE KILLERS

But when the immune response is too strong, NK cells or T-cells can start to attack our own, healthy cells. This is a particular problem for transplant recipients, whose new T-cells can see their tissues as ‘non-self’, causing Graft versus Host Disease.

Our researchers recently identified a protein found in cord blood which could treat skin GVHD and other autoimmune disorders by blocking Natural Killer cells.

“We have known for a long time that cord blood contains soluble factors with anti-inflammatory or immunosuppressive properties – otherwise pregnancy would not be possible because the mother and unborn baby would reject each other,” explains Aurore Saudemont. “But we didn’t know what these factors were.

Now, along with Professor Bernat Soria at the Andalusian Centre for Molecular Biology and Regenerative Medicine (CABIMER) in Seville, Spain, the team at Anthony Nolan has found the culprit – proteins called soluble NKX2D ligands.

“These proteins can be used to disable NK cells or T-cells in other parts of the body, particularly where they can be localised, such as skin GVHD,” says Aurore. “We’re exploring the possibility of a cream containing the proteins, which could be used to alleviate the symptoms of skin GVHD – as well as other autoimmune conditions such as eczema and rheumatoid arthritis – without major side effects. This could be life-changing for patients as their symptoms, such as inflammation, itching and redness, can be a serious problem and are very hard to treat.”

CONTROL TO A T

Another project is looking at harnessing the power of Treg cells to tackle GVHD.

Previous trials in the US and Italy have shown that when Treg cells are injected into a patient at the same time (and from the same donor) as the stem cell transplant, they can inhibit the development of GVHD.

“Our approach is different in that we’re using Treg cells from cord blood, and we’ll treat people who already have GVHD,” says Aurore. “Cord blood contains a lot of Treg cells so you don’t need to grow them for a week before injecting them into the patient, as you would with adult donor cells. That means the cells are younger and fresher, and the therapy is cheaper.”

It’s not a simple process though – it has taken Aurore’s team in Research a lot of hard work to develop the first ever successful protocol to extract the Treg cells from the cord blood. “Cord blood contains more red blood cells, and they tend to stick to other cells and make it difficult to extract, especially when you’re working with a frozen product.”

Trials should start at the end of this year with patients in the UK and Germany who have had a stem cell transplant and developed GVHD, and the team hope to show that GVHD can be controlled with one infusion of Tregs, with relatively few side effects.

“Ideally, we’d stop GVHD developing in the first place, but that’s not always possible, and for some people it doesn’t respond to drugs, so they’re left without any options. We’re aiming to offer these people a new hope.”

You can find out more about the T-control project at www.t-control.info, and there’s more detail on the potential cream for skin GVHD on www.anthonynolan.org
Q&A WITH
NIC ALDERSON

Our Director of Operations Nic Alderson was away for the staff briefing, so we caught up with her to ask about some of the hot topics in Ops at the moment.

How will Third Generation Sequencing change the way we match patients and donors?

‘We heard at the briefing how Operations focuses on patients, customers and donors. Are there any other behaviours that you think will be particularly important for delivering our strategy?’

Nic Alderson said: ‘It’s a fantastic initiative, pre-empting a potential match. These people are more likely to be selected at some point, and we’re further increasing that chance by providing high-level typing up front. It has been really successful and we are now looking at what more we can do to get these donors recruited and onto the register quickly.’

Hopefully we’ll find with the higher level typing that more of our donors will be selected. We know from experience that the better typed the donors are the more likely they are to be selected – we’ve seen that with the phenotype project and the fit panel.

Where both the patient and the donor are typed to allelic level, we’ll get more accurate matches, which I’m sure will have a noticeable impact on outcomes.

At the moment we’re typing around 23% of the stem cell transplant patients in the UK through our Graft Identification and Advisory Service (GIAS), and as part of our strategy we will be looking at whether we can provide this to more transplant centres within and even beyond the UK. GIAS is already a proven, effective service, and with TGS we’ll be able to give people even better matches, giving them the best possible chance of a successful transplant.

Our new strategy talks about improving the flow of information to and from transplant centres. Why is that so important?

We’re also looking at how we can support transplant centres to provide more patient outcome data to the British Society of Bone Marrow Transplants (BSBMT). We’re all working hard to find the best matches and reduce turnaround times but finding out what impact this has had is not always straightforward!

As the one point of contact for all the transplant centres in the UK, we are in a unique position to facilitate and support the transplant community to share data and communicate more.

What about beyond the UK? The strategy also talks about a global technology hub...

We need to have better access to the donors around the world.

The existing system – BMDW (Bone Marrow Donors Worldwide) - is a good hub on which international registries share information about their donors. But others can find matches, but the data it holds is quite limited, and the search system could be better. This has led to some registries and donor centres exploring and developing new ways to share information among themselves.

We’re supporting a drive to develop BMDW so that all registries have equal access to all the donor details and it’s easily available from one system.

BMDW will become one big pot of all 25-million-plus donors where registries can get high-quality information up front and find the ideal match more quickly.

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CASE STUDY: PHENOTYPE PROJECT

Our pioneering phenotype project aims to create a panel of ‘super donors’ so that we can find and provide matches for the most common HLA types more quickly.

We’re enriching the register with allelic-level HLA typing and CMV status ‘up front’ for young men with the 500 most common HLA types. This level of typing would only usually be provided once a donor has been selected as a potential match. When our Donor Liaison team get in touch with the donors to arrange blood samples for the higher-level typing, it’s also an opportunity to check that they are committed to donating if selected.

We are selecting young males as the age and gender reflect international and in-house research into those donors that are most frequently chosen by the transplant consultants for their patients and give the best post-transplant outcomes. These ‘super donors’ typed to high resolution are then likely to appear right at the top of the search report we produce for each patient case – and send to transplant centres.

Since the project began in 2010, 2,096 people have returned a blood sample to be recruited to the panel, and 1,500 of those have been typed to allelic level. The approach is clearly having an impact. In the last financial year (April 2014-15) Phenotype Project donors contributed 12.5% of all donations by Anthony Nolan donors.

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The Services team is the latest team to get up and running as our ‘SMARTLAB™’ prepares to adopt Third Generation Sequencing (TGS) in October. It is the largest team in the SMARTLAB, using a wide range of skills and techniques and dealing with some of the most urgent and difficult tasks.

That’s why Team Lead Finnuala Fowles likes to call her Services team “the impossible team”.

“We’ll deal with all the samples that can’t or won’t fit into the TGS pathway,” explains Finnuala. “We’ll use SSP (Sequence-Specific Primers) and SBT (Sequence-Based Typing) to type samples where we don’t want the ‘6 loci’ typing that TGS provides - such as requests from other registries through EMDIS (European Marrow Donor Information System) - urgent samples such as 24-hour cords, and samples that don’t contain enough cells to work through TGS – those ‘impossible’ samples. We’ll also do commercial work like disease associations and B57 typing, alongside serology, virology and ABO blood grouping and ad hoc tasks such as sex determination for cords” (see box).

The new team brings together people who were involved in different stages of the old typing process, so they buddied up with colleagues to learn the different typing techniques from each other. They recently completed their typing training and have taken on responsibility for the ‘essential numbers’ - urgent and clinical samples.

“Because of the range of techniques we’ll be using, it’s a learning experience for everyone,” says Finnuala. “It’s great for the team to be able to consolidate this phase of training by doing the essential numbers, while starting the next phase - virology and ABO blood grouping.”

As well as all the practical techniques and knowledge, Finnuala says the Services team – and the whole SMARTLAB team – will need to use lots of other skills to deliver the best for patients, donors and customers. “We’ll work closely with the Client team to ensure that we are meeting the needs of transplant centres and internal customers, relying on the Labs Management Team for support and coordinating our efforts with the TGS team. With such a huge range of tasks, we’ll need to use all our teamwork, flexibility, communication and ingenuity to juggle all the different priorities and deadlines and make those tricky samples work, making the impossible possible!

MISSION: POSSIBLE

Just some of the things the Services team will be doing, explained:

- **Virology** – testing donor samples for viruses such as CMV, HIV, Hepatitis B and Hepatitis C once they are selected as a potential match. We’re expecting this work to increase as the higher-resolution typing TGS will give us leads to more of our donors being chosen for transplants.

- **SeroLOGY** – physically combining blood samples to see if a transplant is likely to be successful. Not all alleles are expressed on the cell surface, so samples that are mismatched for these ‘null alleles’ could still work.

- **ABO blood grouping** – ABO type can be important, especially if patients have reduced intensity conditioning (so more of their own cells are likely to survive) or if the patient has antibodies against the donor cell type. In these cases incompatibility can cause delayed engraftment meaning that the patient recovers slower and is transfusion dependent for longer.

- **B57 typing** – the B57 part of the HLA gene indicates hypersensitivity to HIV drugs; HIV clinics pay us to perform this typing so they can tailor patients’ treatment.

- **‘Non 6 loci’ samples**. TGS will type for 6 loci (or parts) of the HLA gene – A, B, C, DR, DQ and DP. Not all registries type for all of these loci, so might request a different typing.
This summer, Anthony Nolan launched its first ever fashion campaign, asking young people to say #IGiveASpit about blood cancer.

We asked our supporters to customise a T-shirt and then share their designs on social media. The T-shirt, which can be purchased on eBay, is not just any shirt - fashion designer Ashish created it for us.

The tongue-in-cheek slogan draws attention to how easy it is to join our register and that by just giving a spit you can help to save more lives. Currently, only 60% of our patients are able to find a perfect match on our stem cell register, so the aim was to inspire more young people and position ourselves as a youth brand through this fashion opportunity.

Several high-profile supporters and celebrities have been inspired to get involved. The Ireland sisters, who launched the Give Our Dad a Bone campaign on social media to find a donor for their father Rob, pledged their support and showed their creativity in making their own T-shirts.

Pop star Amira McCarthy, formerly of girl group Neon Jungle, and Geordie Shore’s Charlotte Crosby joined existing celebrity supporters Tom Holland, Kellie Shirley and Bobby Norris, proudly wearing their unique shirts and saying #IGiveASpit about blood cancer.

This celebrity support helped spread the word about the campaign in national newspapers and magazines, with four pieces of national print coverage.

We also teamed up with 10 bloggers who added their own personal creative edge to the T-shirts, while telling their readers how important and how easy it is to join the register.

The campaign even hit the high street. YR STORE, a fashion brand who have a shop in Topman and Topshop on London’s Oxford Street, offered people the chance to say #IGiveASpit about blood cancer by customising T-shirts using state-of-the-art design and printing equipment. This means the campaign will be seen in the busiest retail shop in Europe, whose customers are largely 16-30 year olds.

The campaign exceeded expectations, with over 1,800 uses of the hashtag and 200 people applying to join the register as a result of seeing #IGiveASpit.
A LIFESAVING PARTNERSHIP

Anthony Nolan’s partnership with the Scottish fire service has recruited an incredible 10% of all the donors on the register in Scotland.

Our partnership started with Strathclyde Fire and Rescue Service almost six years ago. Inspired by Ally Boyle, a firefighter from Strathclyde who was diagnosed with MDS and told he may eventually need a stem cell transplant, a group of fire service employees and volunteers came together to support Anthony Nolan. The group organised donor recruitment and fundraised, both within the fire service and in local communities.

When the fire service became national in 2012, our supporters decided to expand their work too, setting up new groups in Stirling, Dunbartonshire and Ayrshire alongside the existing group in Strathclyde.

Since the partnership began, Scottish Fire and Rescue Service (SFRS) volunteers have raised more than £43,000 for Anthony Nolan and have recruited 6,000 donors, 11 of whom have so far gone on to donate their stem cells and give a patient the chance of life.

SFRS has organised and planned many recruitment events to support patients appealing for more people to register as donors, taking stress and workload away from patients and their families. As well as recruiting donors and raising funds for Anthony Nolan, the volunteer groups also educate young people about donation.

Using their links with local schools and youth groups, SFRS volunteers deliver talks to 16–18-year-olds about what’s involved in being a stem cell donor, followed by donor recruitment events several days later. In the past 12 months, SFRS have recruited 485 students to the Anthony Nolan register at 10 schools.

Amy Bartlett, Regional Register Development Manager for Scotland and Northern Ireland, said: “SFRS is a huge source of support for us in Scotland. Volunteers help educate students about stem cell donation and they are always on hand to support with patient appeals and other events across the region.

“What started as a fairly small core group of volunteers has now grown to a substantial group of motivated and passionate individuals, without whom we would not have the capacity to deliver the breadth of service we have in Scotland.

“With 10% of all donors from Scotland being recruited by SFRS, it is an invaluable partner in our lifesaving work, and this is all done in their spare time as volunteers.”

ALLY BOYLE: PROFILE

- Ally, from Hamilton, was diagnosed with Myelodysplastic Syndrome (MDS) in 2007.
- MDS is a disorder where the production of blood cells by the bone marrow is disrupted, leading to severe anaemia, infections and bleeding.
- MDS can affect red, white or platelet cells and varies in severity.
- Ally suffers from lowered immunity and will need a stem cell transplant in the future to treat his condition.
- Ally was named Recruiter of the Year at the 2013 Anthony Nolan Support Awards (ANSAs).
- Ally recently decided to retire from the fire service but remains a key supporter of the partnership and Anthony Nolan.

In November last year we asked all our volunteers to complete our UK-wide volunteer survey. We wanted to know what we are doing right, but also where we can do things better.

The survey showed that most of our volunteers are happy with their role, feel supported and would recommend Anthony Nolan as a great place to volunteer. However, it also revealed that there is more we can do to keep our volunteers informed and involved in decision-making and consult them about changes that affect their role.

That’s why we are launching a volunteer panel, to make sure our volunteers have their voices heard. By being part of the panel, volunteers will be able to feedback on our work and influence how we develop volunteering at Anthony Nolan. Panel members will be kept up to date about new projects that affect their role, and have the opportunity to provide their views, insight and feedback, either by phone, email or post.

If you volunteer for Anthony Nolan and would like to be part of the panel we would love to hear from you! You just need to be enthusiastic about volunteering and have lots of thoughts and ideas about your experience with us.

Please just drop Liz, our Volunteer Engagement Manager, an email at volunteering@anthonynolan.org or call 020 7284 8250.

REMARKABLE MARROW

Our Marrow student groups are celebrating another remarkable year of recruiting young donors and raising vital funds. Since September 2014, Marrow groups at universities around the country have recruited 12,200 people to the register, and 107 people recruited by Marrow have donated. That’s 31% of all the people who donated in the last 11 months.

It costs £100 to add a potential lifesaver to the register and Marrow groups are doing as much as they can to not only recruit, but also help fund the lifesaving process! From baking to running marathons, Marrow raised over £950,000 last academic year. As well as organising their own events, Marrow members regularly represent Anthony Nolan at supporter events, cheque collections and more up and down the country. Being on the front line for recruitment, fundraising and educating those around them, Marrow are fantastic ambassadors. We simply couldn’t do what we do without them.

Sam Vieira, community fundraiser at Anthony Nolan, says: “I can’t think of a time when a Marrow Group hasn’t been able to say yes and do something extra special for us. It means the world to our supporters and it means so much to me and my team. Marrow is just outstanding to work with.”

You can find out more about Marrow’s lifesaving work on their revamped webpages - www.anthonynolan.org/marrow

VOLUNTEERS: HAVE YOUR SAY
DID YOU DOODLE AT THE STAFF PICNIC?

Thank you. Our Studio team collected 88 doodles from Anthony Nolan staff at our annual picnic, and created badges and stickers based on the designs. Badges have been handed out by Register Development at recruitment events. The idea is that they will start conversations about signing up to the register.