

Registered charity no. 803716 / SC038827

First and foremost

Annual Review 2008



The **ANTHONY**
NOLAN *Trust* 
Taking back lives from leukaemia



The Rt Hon Alan Johnson MP Secretary of State for Health takes pleasure in opening the Anthony Nolan Cell Therapy Centre, Nottingham Trent University. This marks the setting up of the UK's first charitable cord blood programme – both a cord blood bank and a research institute – which will complement the Anthony Nolan bone marrow register. *Photo: Steve Hickey*

We are determined to save lives by providing donors to as many patients as possible whose only hope is a bone marrow transplant.

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Front cover: Paulette was amongst the first mothers to donate their cord blood at King's College Hospital to the Anthony Nolan Cord Blood Programme (See page 14). *Photo: Adrian Meredith*

Dan Snow becomes a potential lifesaver

Dan's story...

“I told my family, several of them are thinking about joining. It’s important to be on the register. There are not enough donors, you have it in your power to save someone’s life.”

Historian, broadcaster and TV presenter, Dan Snow is one of the latest well-known faces to join the Anthony Nolan bone marrow register. Dan, who first appeared on our screens in 2003 presenting a military history series with his father Peter Snow, says; “I first heard about The Anthony Nolan Trust through Adrian Chiles, with whom I’m on ‘The One Show’. He’s been involved for quite some time. I was shocked, actually quite embarrassed, I hadn’t really heard of it. To be on the donor register; it’s such a simple thing for us all to do. And you can save a life. What’s more important than that? It’s fantastic.”

Since that first appearance Dan has gone on to present ‘Battlefield Britain’, ‘Twentieth Century Battlefields’ and more recently ‘Hadrian’. Along the way he’s picked up a BAFTA and written two books to accompany the BBC series. Dan’s burgeoning TV career keeps him constantly on the move – filming for ‘Hadrian’ took him to seven different countries, and his involvement in the early evening magazine programme ‘The One Show’ takes him all over the UK. When not filming he’s writing his next book, a serious history tome on the eighteenth century siege of Quebec. So how did he find time to sign up to the register?

“It took all of 20 minutes, and all I had to do was fill in a medical questionnaire, understand what was involved and give a small blood sample from my arm. That was it, I was on the register as a potential donor. The whole process was quick and painless.”

Dan has a natural and infectious enthusiasm for all that he does in life. This is the man who famously once said “History is the most exciting thing that has ever happened to anyone on this planet!” Fortunately for us, this extends to his relationship with The Anthony Nolan Trust, he’s already spreading the word about our work. “I told my family; several of them are thinking about joining. It’s important to be on the register. There are not enough donors. You have it in your power to save someone’s life.”

Is he scared that one day he may get that call and be asked to donate? Not a bit. “I’m waiting for the phone to ring. I’m not scared about the procedure itself. I’d be nervous if I was asked to donate. But I hope I’d be proud to do my bit.”

Follow Dan’s example, do your bit and support The Anthony Nolan Trust today.



As part of his joining the Anthony Nolan Register, Dan has a small blood sample taken by Lynsey, Donor Recruitment Manager. *Photo: Chris Gloag*

First and Foremost Chairman's foreword



I am delighted to report that in 2008 The Anthony Nolan Trust enjoyed its most successful year since it was established in 1974. It was a year of impressive achievements and of huge contrasts.

First and foremost the Charity gave the chance of life to 758 patients who required a bone marrow transplant. 383 donors from the Anthony Nolan bone marrow register were supplemented by 286 donors from overseas registers and 89 cord blood units which were imported for 67 patients.

This means the Charity now provides the chance of life to two patients every day of the year.

In order to continue this growth and ensure that ever more lives can be saved, the Charity is well on the way to its goal of operating the UK's first charitable cord blood programme. Opening the Anthony Nolan Cell Therapy Centre at Nottingham Trent University, Rt Hon Alan Johnson MP, Secretary of State for Health, paid tribute to the work of the Charity,

Photo: Steve Hickey

"...The Anthony Nolan Trust, for over thirty years, has saved countless lives, not just through campaigning but also through matching potential donors with leukaemia sufferers. The NHS is truly indebted to the Charity for its work over the years, and I'd like to thank it on behalf of doctors, patients and their families today."

The Charity's influence in world scientific research was recognised by the awarding of honorary causa degrees to Professor Madrigal from Odessa University and Nottingham Trent University, and when Professor Marsh was elected President of the European Federation for Immunogenetics (EFI).

Despite the challenging economic conditions the Charity was able to spend more money last year than ever before on providing core services for the benefit of transplant patients; the very purpose for which the Charity exists.

The highs of the record breaking year were tempered by great sadness. The Charity was devastated to lose its Chief Executive Dr Steve McEwan to a road traffic accident in September. You can read more about Steve, who had contributed so much to the Charity's achievements, on the next page.

The Trustees are indebted to Tony Morland, who came back from retirement in France to lead the Charity during this period of

uncertainty until a permanent new Chief Executive could be recruited.

It is a great testament to the Charity's staff and supporters that it has been able to carry on and achieve such great results despite this tragic event. I thank them all.

I am now very confident that The Anthony Nolan Trust is extremely well placed to move forward with the next stage of its development. It has new key staff in place headed by a new Chief Executive Henny Braund whom I am delighted to say joined us at the beginning of January 2009.

As part of its ambitious plans, the Charity is leading the superb campaigning work started by leukaemia sufferer Adrian Sudbury to educate 17-18 year-olds about the value of bone marrow donations and to encourage them to register as potential donors.

I detect a new sense of ambition and determination by everyone involved with the Charity – not least to ensure that we build upon all that was achieved under Steve McEwan's stewardship.

We look forward to your support of our lifesaving work, as the Charity strides forward, first and foremost.

Simon Dyson MBE
Chairman

Dr Steve McEwan BSc, DPhil, FCA 1960 — 2008

“He never stopped thinking about how we could save even more lives.”



It was with great regret that The Anthony Nolan Trust announced the death of its Chief Executive, Dr Steve McEwan, on 15 September 2008 following a road traffic accident.

Dr McEwan led the Charity for the last five years. Joining as Financial Controller, Steve rose within the Charity to become its Chief Executive in 2003. He gained a BSc in Biochemistry and Physiology enhancing his academic credentials with a DPhil from Oxford University. After university he joined PricewaterhouseCoopers, training as a chartered accountant. It was this combination of biomedical training and accountancy that prepared him for a career at The Anthony Nolan Trust. Steve's experience, with his enthusiasm and a healthy dose of scepticism, proved the perfect combination to manage such an organisation.

Simon Dyson, Chairman of The Anthony Nolan Trust paid tribute, “Steve made a huge contribution to the success of this Charity. It was an enormous part of his life and he never stopped thinking about how we could save even more lives.”

Under Steve's leadership, The Anthony Nolan Trust's major developments included the recently opened Cell Therapy Centre, part of the wider Cord Blood Programme. The new facility has the potential to maximise the number of patients who can be treated with a vital transplant, as well as increasing the research into other life-threatening conditions. Professor Ghulam J Mufti, Professor of Haemato-oncology, King's College London, believes that Steve has left an important legacy, “Steve

has given a unique gift of life to so many patients. His dogged determination, leadership, gentle manner and smiling face led to the successful launch of the new umbilical cord cell bank, a fantastic gift not only to leukaemia sufferers in the UK but worldwide. Patients with blood cancers and the staff who care for them will forever remain in Steve's debt.”

A bone marrow donor himself, Steve was keen to ensure that the best resource was available to those needing a transplant. He was always proud to represent the world's first bone marrow donor register across the UK and worldwide.

Steve was an active board member of the World Marrow Donor Association, serving as Treasurer and chairing the Board Budget Committee.

Steve was a great family man and leaves his wife Andrea and young son Sam. His death has come as a huge shock to his family, friends and colleagues at the Charity.

He will be greatly missed by all who had the privilege of meeting him.

Bone marrow donors saving lives

1. Achievement

The Anthony Nolan Trust receives accreditation from the World Marrow Donor Association (WMDA).

What does this achievement mean?

The standards of operation for The Anthony Nolan Trust are recognised as meeting the internationally defined standards of the World Marrow Donor Association. There are 60 unrelated donor registries worldwide and almost as many cord blood banks.

All registries communicate with each other to maximise the potential to find a match for patients all over the globe. Therefore the import and export of donations play a vital role in the success of an unrelated donor transplant programme. This accreditation is reviewed each year and a full inspection and review is held every five years. By ensuring high standards are maintained, WMDA ensure utmost safety for donors and patients.

2. Achievement

The Anthony Nolan Trust received its new licence from the Human Tissue Authority for the adult register.

What does this achievement mean?

The Anthony Nolan Trust has a huge responsibility for individuals from the UK general public who

have been registered as volunteer blood stem cell donors. It is essential that the general public and the scientific and medical communities are satisfied that operating procedures are compliant with national and international legislation. Therefore achieving accreditation with the WMDA and receiving a licence from the Human Tissue Authority here in the UK is essential recognition that the Charity's processes are appropriate. To date, the Charity has provided nearly 7,100 donors; over 5,300 from the Anthony Nolan Register and over 1,700 from other registers around the world.

3. Achievement

383 donors from the Anthony Nolan Register donated either bone marrow or peripheral blood stem cells for patients in need of a transplant.

What does this achievement mean?

This represents the highest number of donors ever provided by the Charity in one year from its own register, since it was founded in 1974. This follows on from 2007 which was also a record year (368 donors). The Anthony Nolan Trust is delighted that it has been able to find matches for increasing numbers of patients who require a transplant, thus saving more lives.

4. Achievement

14,912 donors were recruited onto the Anthony Nolan Register.

What does this achievement mean?

Of the donors recruited in 2008, 42% were male and 75% were under 30. Younger male donors are preferred by the transplant centres that make the original requests. In 2008, 72% of all donations of bone marrow or stem cells were donated by men. The aim is to increase the proportion of male donors on the Register to address an historic bias to females, and to be able to meet the needs of transplant centres treating patients.

5. Achievement

The laboratories remained CPA*and EFI** accredited. Two members of staff received their BSHI*** diploma and one member achieved state registration as a Clinical Scientist.

What does this achievement mean?

Without accredited status the Charity would not be able to provide clinical services (including tissue typing) to transplant centres. CPA and EFI both require evidence that staff are qualified and are being continually educated.

*Clinical Pathology Accreditation

**European Federation for Immunogenetics

***British Society for Histocompatibility & Immunogenetics

Bone marrow donors saving lives

Nigel's story...

"It gives me the incentive to go out each day, knowing that I could be helping someone who can't be helped any other way."

Nigel is a donor recruitment manager for The Anthony Nolan Trust. Nigel's job is to raise awareness of the need for more bone marrow donors, and to run recruitment sessions in north and east England encouraging people to join the Register.

As the Register urgently needs more male donors, and especially from Black and minority ethnic communities, Nigel has been focusing on these groups.

One of the biggest challenges is dispelling some of the myths surrounding bone marrow transplants. "Some people think that to donate your bone marrow it has to somehow be scraped out of your bones – they confuse it with the bone marrow that you give a dog!" Patients seeking a match often contact Nigel because they want to raise awareness of their need for a match. "I can help to give a person and their family hope in the last possible stage of life. It gives me the incentive to go out each day, knowing that I could be helping someone who can't be helped any other way."



Nigel taking a small blood sample from a new joiner to the Anthony Nolan Register.

Sherifa's story...

Sherifa and her colleagues are all qualified counsellors familiar with the host of emotions that might surface...

"You literally read their story, whether they've gone back to school or work, or around the world". Sherifa is talking about the part of her job that she enjoys most – hearing good news from those patients for whom the Charity has, quite literally, given a new lease of life. Sherifa is one of three donor welfare officers who work alongside the harvest co-ordinators offering practical advice and emotional support to donors. They also act as the point of contact between the recipient and donor.

Sherifa recalls a recent donor who became very emotional when she discovered she was donating to help save a child's life. "She was so worried about the child's future." The donor had had difficulties conceiving, and now a mother, it brought a host of emotions to the fore. "A year later she received a card; and on the front of the card was the child's handprint. It made her year."

Sadly, the news is not always good, and in those instances the donor welfare officer has the difficult task of breaking the news to donors. Sherifa and her colleagues are all qualified counsellors familiar with the host of emotions that might surface, "For some it opens up memories of recent deaths in their own family." For Sherifa it's all in a day's work.



Sherifa on her way to visit a donor. Photo: Steve Hickey

Bone marrow donors saving lives

Farah's story...

Farah is a woman on a mission. She's determined to get more potential donors from ethnic minorities to join the Anthony Nolan bone marrow register.



Farah with her son Dean

"I wore Anthony Nolan t-shirts all the time, then I realised the real problem was making Asians and Arabs more aware." While sitting in hospital with her son Dean, she decided to create a website aimed at Asian and Arab communities. Taking its name from the Arabic word for 'life' she formed the Hayat Bone Marrow Trust (www.hayatbmt.org.uk) which campaigns for more people from ethnic minorities to join the register, and for the government to make the collection of cord blood more widespread.

Farah's son has two complicated conditions. He was born with Dyskeratosis Congenita. His body does not produce enough bone marrow, making him prone to a wide range of cancers. He can't talk properly and uses a wheelchair. Doctors have also diagnosed Hoyeraal Hreidarsson syndrome – a condition that generally includes aplastic anaemia and immunodeficiency. The combination of these illnesses is extremely rare.

Dean, a sociable 8 year old communicates using a system known as Makaton. His future health is a cause for concern as he is so vulnerable to a wide range of illnesses. Farah says "A bone marrow transplant would give him a better quality of life." Dean spends more of his life in hospital than at home.

His school record for last year showed a 33% attendance record, with August spent entirely in hospital. As his only full-time carer Farah is always at his side.

Farah started the Hayat Bone Marrow Trust in her attempt to find Dean a bone marrow donor, but in the process met other families in the same situation. She describes herself as the 'crazy woman' who hands out cards featuring Dean's photo and details of the register to everyone she meets. She's attended clinics; like the one at London Central Mosque, where The Anthony Nolan Trust worked in partnership with the ACLT*. The Imam made a plea to the 5,000 who attended Friday prayers to join the register. Farah plans to find venues for clinics in London areas like Southall and East Ham which have a high population of ethnic minorities.

"Despite our efforts there are still not enough Asians on the register. These things need to change. We can make a difference."

Farah hopes that a match will be found for Dean. Whatever happens, she is determined to make more people aware of the need for potential donors. She won't rest until the chances of finding a match are 100%. "This is the mission for the rest of my life now."

*African Caribbean Leukaemia Trust

Bone marrow donors saving lives

Charles' story...

When a year later the call came to say he was a 'perfect match' he recalls how his mind was already made up. "I'd gone through all the issues the previous year, I was there in a heartbeat."

Charles vividly recalls the moment when two student reps interrupted dinner in his hall of residence to urge students to consider joining the Anthony Nolan Register. "They climbed onto two chairs and tapped a glass to get our attention. Approaching us during dinner was inspired; it meant they had a captive audience." For Charles and his friends the message was a powerful one, "I heard the words 'leukaemia' and 'saving a life' and didn't think any more, we all signed up to join the register on the spot. I suppose in retrospect I was quite naive, it never occurred to me that I could actually be a perfect match for someone." But that is exactly what Charles turned out to be.

Three years later Charles had graduated and moved to London when he got that call. "I'd been called the previous year and asked to give some more blood samples as there was a possibility I was a potential match." Charles opted to donate using the newer method of

peripheral blood stem cell collection rather than by a bone marrow harvest. "The injections left me a little sore with aching bones, but it was no more than I'd usually experience after a hard game of rugby." During the harvest he watched films on a borrowed laptop and was back at work the following Monday.

Throughout the process, those whose lives have tragically been affected by leukaemia spurred Charles on. "I remember lying in bed in the Oncology Department at University College Hospital surrounded by seriously ill patients. In the next bed a man suffering from leukaemia turned to me and said 'what you're doing is such a tremendous thing.' I knew then, I'd made the right decision."

His message to those considering joining the register is simple. "You know the devastating impact leukaemia can have on a family – we can do something to stop it – encourage everyone to get involved." Charles is continuing to support The Anthony Nolan Trust by running the Flora London Marathon in 2009.



Charles and his young brother Tristan

Bone marrow donors saving lives

Lisa's story...

Lisa's story is an inspiration to us all. "The doctors said I might last five years without a transplant. That means I could have been dead by now."

It's difficult to believe that Lisa was ever seriously ill. Today she is the picture of health and vitality enjoying a challenging career as a police officer with the Metropolitan Police. In her spare time she plays volleyball for the British police team and runs. She is married to a police officer and they are both volunteer helpers with the Redbridge volunteer police cadets. Yet seven years ago she was diagnosed with myelodysplasia and told that it would develop into acute myeloid leukaemia and that without a transplant she would die.

Lisa had gone to the doctor after developing a strange rash on her foot after returning from a walking holiday. Tests revealed she had a low platelet count and Lisa was referred to a specialist. It took another year before she was given the devastating diagnosis at the age of 21. Apart from the rash she felt fine, but doctors advised her that her best chance of survival



Lisa with her husband Alistair on the slopes in Andorra.

was to have a transplant immediately. Using The Anthony Nolan Trust, they had already found her a donor. Following a course of chemotherapy Lisa had the transplant. After weeks in hospital she made a full recovery and was given the all clear in 2006. "I'm 100% better now – I feel completely fine. Good things have come out of this. I've always been sporty but this summer I went to Bangkok to compete in the Transplant Games – like a mini Olympics for people who've had transplants. I won gold in badminton and silver in the 3km road race. That was fantastic."

Very much alive, Lisa ran a marathon in 2004 and continues to support The Anthony Nolan Trust. "They do an amazing job, and I'll do whatever I can to support the Charity. I'll never forget what they've done for me."

Bone marrow donors saving lives

Beryl's story...

"The job gives me a personal feeling of connection with every patient and what they're going through. I know it's only a small part but I do still feel part of it."

Beryl, who had nursed since she was 16, retired in 2006 and admits suffering from 'empty nest syndrome' after her two children had left home for university. Prompted by an advert in a nursing magazine she eventually became one of the Charity's volunteer couriers. "I needed a new project and this was a golden opportunity to have some time on my own away from home, and a chance to travel. Who wouldn't want to do it?"

Since then she's made many deliveries for the Charity (over 30 in 2008) flying to Tasmania, Canada, New York and, more frequently, all over Europe. A journey begins with a call from Rochelle, the Charity's Harvest and Welfare Manager who gives Beryl the details of the journeys she needs to make. "This involves going to a collection centre, picking up bone marrow or stem cells and delivering it to a hospital or laboratory for transplantation."

As the bone marrow or stem cells need to be delivered within a specific deadline all Beryl's flights are booked for maximum flexibility in case something should go wrong. She recalls the day a plane overshot the runway at Heathrow whilst she was flying into London from Germany. "The pilot announced that we were making our descent, but I've arrived there so many times I could tell we were turning around." Realising something was wrong she approached the cabin crew who confirmed that they were indeed returning to Germany. After Beryl had explained the importance of her journey the crew were soon arranging her next flight from Germany to London City, ensuring she was able to make her vital delivery on time.

The precious bone marrow or stem cells are carried in a plastic ice-box which Beryl has to keep within her sight at all times. Although she has paperwork explaining the contents of her ice-box (and the need for it to be exempt from x-ray), navigating through security hasn't always been easy.

A recent trip to Spain found her confronted by a security guard who refused to read the paperwork. Fortunately, a fellow passenger glimpsed the Anthony Nolan stickers on her box and came to her rescue pleading her case in Spanish for over half an hour until the guard was eventually persuaded to let her pass. "Those



who are my age often remember Shirley Nolan making a plea for her son Anthony years ago, and come and talk to me. Others joke and ask whether I've got a few cold beers or an organ inside the box! It's a great opportunity to talk about The Anthony Nolan Trust and what they do."

In at the birth

Terie's story...

“Cord blood is important because it is so rich in stem cells. These cells can be given to people suffering from disorders such as leukaemia; giving them the chance of life.”

Terie thinks she has the best job in the world. As the Collection Facility Co-ordinator at King's College Hospital (KCH) she is responsible for promoting and organising the collection of cord blood at King's College Hospital's maternity unit, or as Terie puts it, “making the cord blood programme happen.” “If you feel inspired and enthusiastic it doesn't feel like a job. This concept is so simple – being creative and making it all happen is brilliant.” Terie works closely with Professor Sergio Querol, Director of Cord Blood Services at The Anthony Nolan Trust to deliver information to women giving birth at KCH to advise them about donating their cord blood. “Cord blood is important because it is so rich in stem cells. It is ostensibly a waste product that is just thrown away after the baby is born. Those stem cells can be given to people suffering from disorders such as leukaemia giving them the chance of life. For me it's recycling at its best.”

Much of her work over the last 18 months has been training health professionals about the programme and also in the practicalities of taking cord blood samples. The first collection was taken on Christmas Eve 2007. “It was the most exciting moment – the culmination of what we'd been working towards.” So far this year around 160 women have consented to have their cord blood taken. Of these, collections were made from around half of them. Women donate anonymously to the register and where there is not enough of

a sample for a transplant, the blood will be used in stem cell research. Terie says, “women are realising how quickly science is moving and that stem cell research has the potential to provide cures for sickle cell anaemia and diabetes. This knowledge is spurring women on and motivating them to donate.”

KCH was originally chosen for the project as its expectant mothers come from a diverse mix of ethnic groups including those that are currently poorly represented on the Register.



Terie (lower right in red trousers) surrounded by mums who have donated their cord blood to the Anthony Nolan Cord Blood Programme. Photo: Adrian Meredith.

Searching for those vital matches

Helen's story...

“New technology will give us the potential to achieve more rapid higher resolution typing, which will speed up the process of finding a donor. Our newly established cord blood bank also provides us with an alternative source of donors.”

Helen is head of the Anthony Nolan Histocompatibility Laboratory's Clinical Services team whose job it is to tissue type patients in need of a donor. Often the search begins with family members, especially siblings, who offer the most likely match. Their tissue typing will also be undertaken by Helen's team. If no match can be found within the family a search of the Anthony Nolan and other UK registers will be instigated. The search will often be extended to overseas registers. If a potential donor is found on one of the registers, the Clinical Services team will perform confirmatory tissue typing to ensure accurate matching. During her 22 years with the Charity Helen has seen many changes to the way the laboratory works. “My job has changed significantly – the technology continues to evolve. In the early days we were working at the cellular



Helen discussing laboratory data with her colleagues.
Photo: Steve Hickey

level. Today we mainly use DNA technology to look inside a cell; giving us a more detailed analysis, hence a much closer match”.

For the future Helen sees that advances in technology will continue to make her work even more efficient.

The addition of the cord blood bank has impacted on the team's workload this year as cord blood samples are sent to the laboratory for tissue typing. However, Helen and her colleagues are used to the frenetic pace. “Throughout my 22 years the laboratory has always been busy. I enjoy the challenge of meeting strict deadlines with the help of a dedicated team. It's very satisfying knowing that every day you are making a real difference to someone's chance of survival – and there are not many jobs you can say that about.”

World class research; lifesaving advances

The Charity's research is having an increasingly beneficial impact on the lives of many patients. While more lives are being saved, so there is a greater determination to carry out the highest quality research to save even more.

1. Achievement

Significant advances in understanding of the factors that contribute to the outcome of stem cell transplantation.

This work has been led by Steven Marsh, who was recently appointed Professor of Immunogenetics at University College London and recognised for his international leadership in the field by becoming President of the European Federation for Immunogenetics (EFI). The Immunogenetics Group has published new research on the consequences of matching classical histocompatibility genes such as HLA-DP, as well as the non-HLA gene NOD2/CARD15.

What does this achievement mean?

The insights from this genetic research help to identify donors whose bone marrow is less likely to be rejected. Such understanding will enable The Anthony Nolan Trust to improve on the clinical use of stem cell therapies to increase patient survival and quality of life. The Immunogenetics Group, working closely with other research groups headed by Dr Bronwen Shaw and Dr Ann-Margaret Little, has worked to establish the largest database of HLA* genes in the world, which acts as the international reference. Coupled with donor-patient data and long term clinical follow-up the database has allowed the groups to publish a number of important studies that promise to make a significant impact on stem cell transplantation.

2. Achievement

A new methodology for obtaining large numbers of regulatory T cells from cord blood units.

What does this achievement mean?

These cells control different aspects of the immune system. In the future the Charity will not only be able to use regulatory T cells to treat rejection but also to treat a number of other inflammatory systemic disorders and help to achieve higher rates of stem cell engraftment. This will be particularly important for patients for whom an appropriate bone marrow match has not been found.

3. Achievement

A research study in the UK has been carried out to improve understanding of the optimal number of cord blood units required for treating patients.

This work, headed by Director of Cord Blood Services Dr Sergio Querol, has included work to validate and optimise the conditions required for collection and provision of cord blood for treating patients.

What does this achievement mean?

Such studies help improve understanding of cord blood banking and have wider national implications. Discussions have been held with the Department of Health and the NHS Cord Blood Bank about how best to exploit the research findings and to ensure that a UK resource can be created that aims to meet the needs of 80% of patients requiring transplantation.

4. Achievement

The piloting of a new Graft Information Advisory Service (GIAS) to share the Charity's knowledge of graft identification.

A team made up of scientists from the Immunogenetics Group, Dr Sergio Querol and the donor recruitment experts from the Charity's Operations Department, works closely with UK transplant centres in the search and procurement of the best stem cell transplant option for all patients, using the knowledge gleaned from ongoing research studies on the outcome of UK patients.

What does this achievement mean?

This new service means that the best possible graft for a patient can be identified, taking into account the results of research and practice outcomes. This will aim to improve the level of success for patients and reduce the possibility of graft rejection; a major factor contributing to the death of transplant patients.

5. Achievement

A study has been initiated to understand more clearly the role of granulocyte colony stimulating factor (GCSF) on stem cell mobilisation.

In collaboration with Dr Ellie Nacheva at the Royal Free Medical School, and with advice from University College London, this study has the sponsorship of The Anthony Nolan Trust, British Bone Marrow Registry, World Marrow Donor Association, Chugai and Amgen. Under the co-ordination of Trudy Ahyee, the Charity's Clinical Trials Co-ordinator, recruitment for donors for this study has started.

*Human leukocyte antigen

World class research; lifesaving advances

What does this achievement mean?

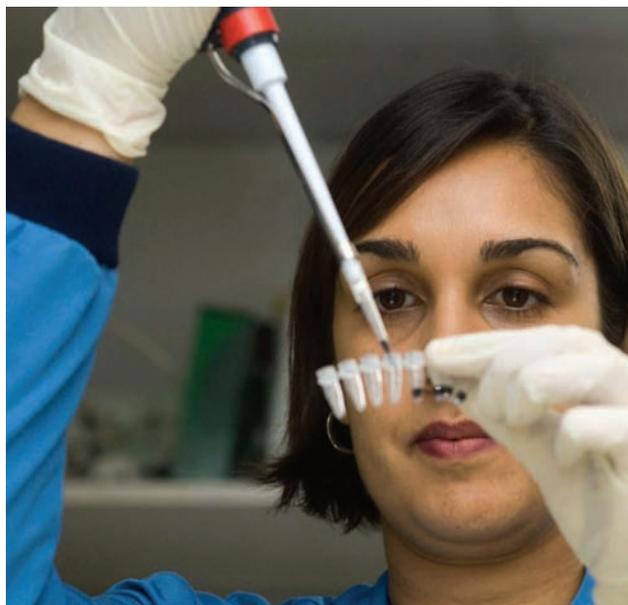
This drug is given to donors five days before stem cells are collected. A better understanding of the use of GCSF will improve knowledge and ultimately ensure the utmost safety of donors.

6. Achievement

The completion of the Allostem project. During the past four years this EU funded project, led and co-ordinated by Professor Madrigal, allowed centres from more than 29 countries to work closely on research projects related to haematopoietic stem cell transplantation (HSCT), with outstanding results.

What does this achievement mean?

AlloStem has resulted in 20 clinical trials being initiated throughout Europe, over 400 publications, and the training and mobilisation of more than 100 research scientists. Once the trials are completed, AlloStem will have made a significant impact on HSCT worldwide. It is anticipated that it will make a substantial difference to the lives of many patients.



Neema sets up an experiment that will help to identify novel genetic factors that could lead to an improved outcome for recipients after transplantation. *Photo: Steve Hickey*

Neema's story...

We are looking at what makes the best donor and how we can improve survival rates.

Neema is a research assistant at the Anthony Nolan Research Institute. In 2007 she was named BSHI* Young Scientist of the Year. “My work, with others, is helping us understand what makes the ‘perfect’ donor and how we can use this information to select the most appropriate donor for each patient. Understanding the genetics of transplantation may mean that the pool of suitable donors is far larger than it may otherwise be, offering the chance of survival to many people still waiting for the ‘perfect’ donor.

“Whilst we know that those patients who have a donor described as a ‘perfect match’ have the best chance of survival, we know that things sometimes go wrong, so the survival rate is not 100%.

“We also know that some patients receiving a mismatched donation survive and do well. We are looking at what makes the best donor and how we can improve survival rates.

“It could take years for us to answer the questions that we pose at the beginning of our projects. For me, knowing that what I am doing today may help save one or hopefully many lives is something that I can’t ignore.”

*British Society for Histocompatibility & Immunogenetics

Immunogenetics Group led by Professor Steven Marsh, Deputy Director Immunogenetics. Neema Mayor, Louise Cooke, James Robinson, Dr Jennifer Schellekens, Simon Richardson, Kavita Mistry, Hazael Maldonado Torres, Marjorie Lawton

Immunotherapy Group led by Professor Alejandro Madrigal. Dr. Daniel Figueroa, Dr Richard Duggleby, Dr Jim Devitt, Lia Zambetti, Mehri Daryouzeh

Anthony Nolan Cord Blood Programme led by Dr Sergio Querol. Dr Susana Garcia, Dr Roger Horton, Rob Davey, Laura Fry, Daniel Gibson, Salmah Mahmood, Terie Duffy, Maria Tario

Scientists and students visiting from abroad. Dr Uma Kanga, Dr Esteban Arrieta, Dr Nastya Savilova, Dr Javier Fernandez Torres, Dr Marie Schaffer, Jean-Phillipe Barnier, Fernanda Cerda

Working in partnership with: Royal Free and University College Medical School, King’s College London, Royal Marsden Hospital, Nottingham Trent University and Stanford University.

Raising funds; raising hopes

1. Achievement

Two major new corporate supporters, BGC Partners and Man Group, supported the work of The Anthony Nolan Trust in 2008.

BGC began a charity trading day after the 11 September attacks to raise money for victims' families. The day has become an annual event with the proceeds being split between ten different charities each year. This is the first year that the Charity has been nominated to receive funds.

Man Group chose to work more closely with the Charity as its nominated charity. In addition to a generous £100,000 donation, all funds raised by their staff through events such as sponsored marathons will be donated to The Anthony Nolan Trust. Man Group is also holding donor recruitment clinics in the workplace.

What does this achievement mean?

This achievement allows the Charity to generate funds in excess of £200,000 by promoting its work to two large employee groups. It also provides the opportunity to recruit new donors to the bone marrow register through the promotion of donor recruitment clinics.

2. Achievement

In excess of £5million in voluntary funds has been raised. Voluntary funds refers to money raised by fundraising events and donations rather than the income the Charity receives in fees for its work such as providing donors from its register.

What does this achievement mean?

This achievement means that the Charity can fund the activities of its donor recruitment team, building the number of potential donors available, thus providing more opportunities for those in need of a lifesaving transplant. The Cord Blood Programme has received funding, enabling the collection and storage of stem cells from umbilical cords to provide another valuable source for transplants.

3. Achievement

Continued improvement and development of regional fundraising activities.

What does this achievement mean?

Following the introduction of a change programme for regional fundraising in 2007, the Charity has significantly reduced the costs of event fundraising. There has been a focus on profitable events with opportunity for growth, and new events developed, delivering additional income. This means that a higher net return for each activity has been achieved

and that overall the contribution made to fund charitable activities is greater. An example of this is the Three Peaks 24 Hour Challenge which has generated over £100,000 of additional income and leads to other opportunities for UK challenge events in the future.

4. Achievement

Securing a third year of support with easyJet and Travelex generating over £600,000.

EasyJet distributes leaflets on board its flights and collects foreign loose change from passengers. Travelex count and bank the money for the Charity, charging a fraction of the normal costs for this service.

What does this achievement mean?

This achievement helps the Charity on many different fronts. Firstly, the profile that is generated by the continued relationship with easyJet helps us to reach thousands of passengers and, therefore, potential new donors. Secondly, the partnership allows The Anthony Nolan Trust to work across European borders with registers in Germany, Switzerland, France, Spain and Italy. Thirdly, the success of the relationship over three years has generated nearly £2million so the Charity can fund areas of work from donor recruitment to research and the development of new projects like the Cord Blood Bank Programme.

Raising funds; raising hopes

Julie's story...

Like many, Julie knew little about The Anthony Nolan Trust until it affected her own family but her energy and commitment to “being proactive” are making a real difference.

Julie knows only too well the strain that living with leukaemia can bring to a family. Ten years ago her sister Melinda's husband, Steve, was diagnosed with acute myeloid leukaemia and given just two weeks to live. Steve underwent six months of chemotherapy which gave him five years in remission from the disease only for a different strain to return. Following more chemotherapy Steve is again in remission, but should that change his only hope of survival is a bone marrow transplant. Steve, like so many others, needs to find a match.

Julie says “I felt useless. I just couldn't sit around and do nothing to help. I had to be proactive.” Julie set about organising a donor recruitment clinic at her nephew's school in Frimley Green to attract more donors to the register. The event attracted over 300 potential donors; a terrific achievement.



Since then Julie has raised close to £30,000. For two consecutive years she commandeered friends and colleagues to take part in one of the Charity's dragon boat racing events and last year Julie organised a ball at Pinehill Golf Club, Surrey, raising £9,500 in one night. Despite her full-time job as sales director, Julie is busy for 2009, planning an 'It's a Knockout' style fundraising competition.

Financial summary

Income £22,250,712



■ Sourcing overseas donors , fees received for searching overseas registers for donors for UK patients	£8,121,177	(2007: £5,399,343)
■ Recharging donor provision , fees received for services such as the provision of donors from the Anthony Nolan Register to transplant centres	£7,105,261	(2007: £6,463,273)
■ Voluntary income , donations from individuals, corporate supporters and trusts and other similar institutions, and from legacies	£5,160,417	(2007: £4,733,978)
■ Fundraising , income from Anthony Nolan Marketing Ltd. from the sale of merchandise, advertising, the organisation of fundraising events, and by exploiting intellectual property and other similar rights held by the Charity	£1,164,664	(2007: £1,416,478)
■ Research grants , funds received for research projects.	£547,344	(2007: £483,777)
■ Investment returns comprise rent received, bank interest on short term deposits and royalty income	£151,848	(2007: £158,853)

Expenditure £ 22,234,560

How we spend our income to carry out our lifesaving work

£7,627,464 (2007: £5,176,638)



Sourcing overseas donors, costs incurred for searching overseas registers for donors for UK patients

£5,228,350 (2007: £4,812,780)



Recruiting donors, the costs for recruiting, testing and supporting potential donors on the Anthony Nolan Register

£4,777,711 (2007: £4,767,578)



Providing donors, the costs incurred when the Charity searches for and provides donors from the Anthony Nolan Register to transplant centres

£2,548,964 (2007: £1,233,854)



Fundraising, costs incurred by Anthony Nolan Marketing Ltd., plus direct and support costs in developing much of the Charity's voluntary income

£1,737,348 (2007: £1,233,854)



Research, the Charity's research to improve the effectiveness of bone marrow transplantation

£314,723 (2007: £251,734)



Governance, the costs of administering the Charity

The figures in this financial summary are consistent with those provided in the audited full annual report and financial statements. For full details contact Tony Farnfield, Director of Finance and Administration, The Anthony Nolan Trust, Heathgate Place, Agincourt Road, London NW3 2NU. 020 7284 1234.

Trustees and senior personnel

Our trustees

1. Mr Simon Dyson MBE, FCAA, Chairman
2. Mrs Fran Burke BA
3. Mr Lionel Cashin
4. Mr Peter J. Harrison
5. Mr Ian Krieger BA, FCA, MSI
6. Dr Colin Rickard, PhD, MA, FRICS
7. Professor K Michael Spyer DSC, MD(Hon), FmedSci
8. Mr Brian Turner CBE



Ian Krieger and Brian Turner CBE – Allan Jones. Colin Rickard, Fran Burke, Simon Dyson MBE and Peter J. Harrison – Simon Hickey

The Anthony Nolan Trust Joint Scientific and Medical Advisory Committee

Chaired by The Anthony Nolan Trust's Medical Director this committee is an independent group of acknowledged expert scientists and doctors offering advice and guidance to The Anthony Nolan Trust. We thank them for their dedication.

Chair: Professor John Goldman
DM, FRCP, FRCPath, FAcadMedSci

Professor Jane Apperley
MBChB, MD, FRCP, FRCPath

Professor A.J. Barrett
MD, FRCP, FRCPath (Bethesda USA)

Malcolm K. Brenner
MA, MB, BChir, PhD, FRCPath

Professor C. Craddock
DPhil, MRCP, FRCPath

Professor Stephen Mackinnon
MD, FRCP, FRCPath

Professor P. Moss
MB, BS, PhD, FRCP, FRCPath

Professor N.H. Russell
MD, FRCP, FRCPath (Nottingham)

Professor John Trowsdale
PhD, FMedSci

Professor H. Waldmann
MD, FRS, PhD, MRCPath(Oxford)

Dr. Paul Veys
FRCP, FRCPath, FRCPCH

Dr David Marks
MB, BS, PhD, FRACP, FRCPath

The Anthony Nolan Trust Senior Management Team @ 31 January 2009

Henny Braund
Chief Executive

Tony Farnfield
Director of Finance & Administration

Professor Goldman DM, FRCP, FRCPath, FAcadMedSci
Medical Director

David Knights
Director of Marketing & Communications

Professor Alejandro Madrigal MD, PhD, FRCP, FRCPath, DSc
Research & Scientific Director

Pauline Makoni BSc, MBA
Director of Operations

Dr Ann-Margaret Little BSc, PhD, SRCS, MRCPath
Director of Operations until 9 January 2009

Mark Smith
Director of Fundraising until 28 November 2008

The Anthony Nolan Trust enjoyed its most successful year since it was established in 1974. The Charity was able to spend more money in 2008 than ever before on providing core services for the benefit of transplant patients.

With grateful thanks

Friends of The Anthony Nolan Trust

Anthony Nolan Friends are formally constituted groups of volunteers who support our work throughout Britain in a variety of ways: helping at donor recruitment clinics, offering financial donations, organising fundraising events, providing valuable gift and services in kind. We are immensely grateful for all their hard work.

Aberdeen Sheriff Court, Aberfoyle, Ashbourne Baildon, Bexley and Orpington, Bournemouth Bridge of Allan, Carlisle, Croydon, Dunfermline Sheriff Court, East Lothian, Fife, Glasgow District Court, Guernsey, Halesowen, Hitchin, Isle of Arran, Isle of Man, Jedburgh Sheriff Court, Jersey, Kirkcaldy Sheriff Court, Linlithgow Sheriff Court, Long Eaton, Newport on Tay, Nuneaton, Oban, Orkney, Sale, Salisbury, Scarborough, Sunderland, Swaffham, Weardale, Winsford



Marrow is a volunteer student organisation that aims to give every UK student the opportunity to join the Anthony Nolan Register. Marrow activities include organising bone marrow donor recruitment clinics, raising funds and raising awareness of the Charity's work.

National Marrow Chair 2008/9

University of Newcastle Marrow

Scotland and Northern Ireland University of Aberdeen Marrow, University of Dundee Marrow, University of Edinburgh Marrow, University of Glasgow Marrow, University of St. Andrew's Marrow, Queen's University Belfast Marrow

London Barts and The London School of Medicine Marrow, King's College London Medical School Marrow, Imperial College London Marrow, St. George's, University London Marrow, University College London Marrow

South East University of Cambridge Marrow, University of Oxford Marrow, University of Southampton Marrow, University of East Anglia Marrow, Brighton and Sussex Medical School Marrow

South West University of Bristol Marrow, Cardiff University Marrow, Peninsula Medical School Marrow, Swansea University Marrow

North East Durham University Marrow, Hull and York Medical School Marrow, University of Leicester Marrow, University of Newcastle Marrow, University of Nottingham Marrow, University of Sheffield Marrow, University of Warwick Marrow

North West University of Birmingham Marrow, Keele University Marrow, University of Leeds Marrow, University of Liverpool Marrow, University of Manchester Marrow

Charitable Trusts and Foundations 2008

The Anthony Nolan Trust gratefully values the financial support of many charitable trusts and foundations around the UK, of which the following are a selection.

David Uri Memorial Trust, G & E Pollitzer Charitable Settlement, Maud Elkington Charitable Trust, Michael Shanly Charitable Trust, Raymond & Blanche Lawson Charitable Trust, Reuben Foundation, The Annandale Charitable Trust, The Charles and Elsie Sykes Trust, The George A Moore Foundation, The Fulmer Charitable Trust, The Hon Mrs Kathleen Laurence Charitable Trust, The Houghton Dunn Charitable Trust, The Inman Charity, The Jane Hodge Foundation, The Jessie Spencer Trust, The Jones 1986 Charitable Trust, The Klahr Charitable Trust, The Lady Hind Trust, The Linmardon Charitable Trust, The Morton Charitable Trust, The Peter Courtauld Charitable Trust, The Sir James Roll Charitable Trust, The Sir Jules Thorn Charitable Trust, The Souter Charitable Trust, The Steel Charitable Trust, The Thomas Farr Charity, The Ursula Keyes' Trust

... and our many volunteers who support the Charity in so many different ways and make our work possible.

With grateful thanks

Corporate Supporters

The Anthony Nolan Trust continually relies on support from business and other organisations. Here is a cross section of our corporate supporters during 2008. Our sincere thanks go to these and many others.

3C Technology, Aegis, APS Group, Art & Soul Glasgow, Associated Newspapers, Astus UK Ltd, Baker Tilly, Barclays Bank, Belfast Telegraph, BGC Partners, Brenmo Plants Cash & Carry, Cargill Cotton, Charles Hurst Group, Cheshire Building Society, Coolfun Ltd, Circus Starr, CVD Ltd, Deloitte, Dunfermline RFC, Dunfermline Round Table, Eastern Airways, Eastern Digital Exhibition and Display, easyJet, ETM Limited Manchester & Mr Derek Acorah, Europackaging Ltd, Feckin Whiskey, Flybe, Funds Europe, Furniture Village, Greybar Design, Grosvenor House, Handelsbanken, Halfords, Hastings Hotels, Hotels4U, House of Dorchester, Incisive Media, John Lewis, Kingsbarns Golf Links, Kleinwort Benson, Lagan Holdings, Legal & General, Lifetime Mortgages, Llanllyr Water, Lloyds Pharmacy, Long Rake Spar, Lothian Estates, Jedburgh, Man Group plc, Mark Ramprakash Benefit Year, Mars, Metro, Minghella Ice Cream, Mirabaud Securities, Mulholland Contracts Ltd., Musgrave Group, National Museums Northern Ireland, National Sporting Club, NJO Leds, North East Telecommunications Ltd, Oase UK Ltd, PalletFORCE plc, Parkstone Bay Marina, Pennine Print Ltd, Pernod Ricard, Powerboat Training UK, Press & Journal, Protherics plc, Pure Recruitment Solutions, Robert Dyas, Royal Bank of Scotland, RT Marketing Ltd, Scottish Borders Council Museum and Gallery Service, Selsius Ltd, Speedy Hire, Stena Line, Steve Thompson Benefit Year, Suffolk Offset, Sunningdale Golf Club, The Glenmorangie Company Limited, The Royal Bank

of Scotland Manufacturing HR Department, Edinburgh, The Sands Venue, T-Mobile, Torrent Trackside, Translink, Travelex, Travis Perkins UTV, VH BIO Ltd, VU Ltd, Wilkinson

We are grateful for the personal involvement in our lifesaving work of these high profile supporters:

David Aaronovitch	Leon Lopez
Christina Bailey	Tim Lovejoy
Richard Blackwood	Orlaith McAllister
Georgina Bouzova	Aiden McCardle
Edith Bowman	Liz McClarnon
Dominic Brunt	Michael McKell
Will Carling OBE	Scott Mills
The Cheeky Girls	Neil Oliver
Adrian Chiles	Omar
Chris Chittell	Belinda Owusu
Olivia Coleman	Femi Oyeniran
Rachael Cordingley	Craig Phillips
Penelope Cruz	Patricia Potter
Lawrence Dallaglio OBE	Cassie Powney
Les Dennis	Mark Ramprakash
Sara Dhada	Julian Rhind-Tutt
Noel Edmonds	Dougray Scott
England Rugby Squad	Kellie Shirley
Jessica Fox	Dan Snow
Angus Fraser	Snowboy (Mark Cotgrove)
Mark Goodier	Di Stewart
Will Greenwood	James Sutton
Mel Guidroyc	Meera Syal
Amanda Hamilton	Hannah Tointon
David Harewood	Kara Tointon
Richard Hill MBE	Kevin Mark Trail
Greg James	Brian Turner CBE
Jeremy Lewis	

To be on the donor register; it's such a simple thing for us all to do. And you can save a life. What's more important than that? It's fantastic."

Dan Snow

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VH Bio is proud to supply The Anthony Nolan Trust with HLA tissue typing reagents, vital tools in the bone marrow transplant process. The publication of this annual review was made possible by the generous financial support of VH Bio Ltd.

All information in this review is correct at time of going to press. All figures quoted in this review refer to the calendar year 2008, except those on page 20 which refer to the Charity's financial year ended 30 September 2008.

Design: The Surgery; Copywriting: Suzanne Kershaw; Printing: Suffolk Offset;
Paper Supplies: We thank the James McNaughton Group for their generous help with the supply of Perfect Image.
This publication contains fibre from forests certified according to the principles of the Forest Stewardship Council.



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