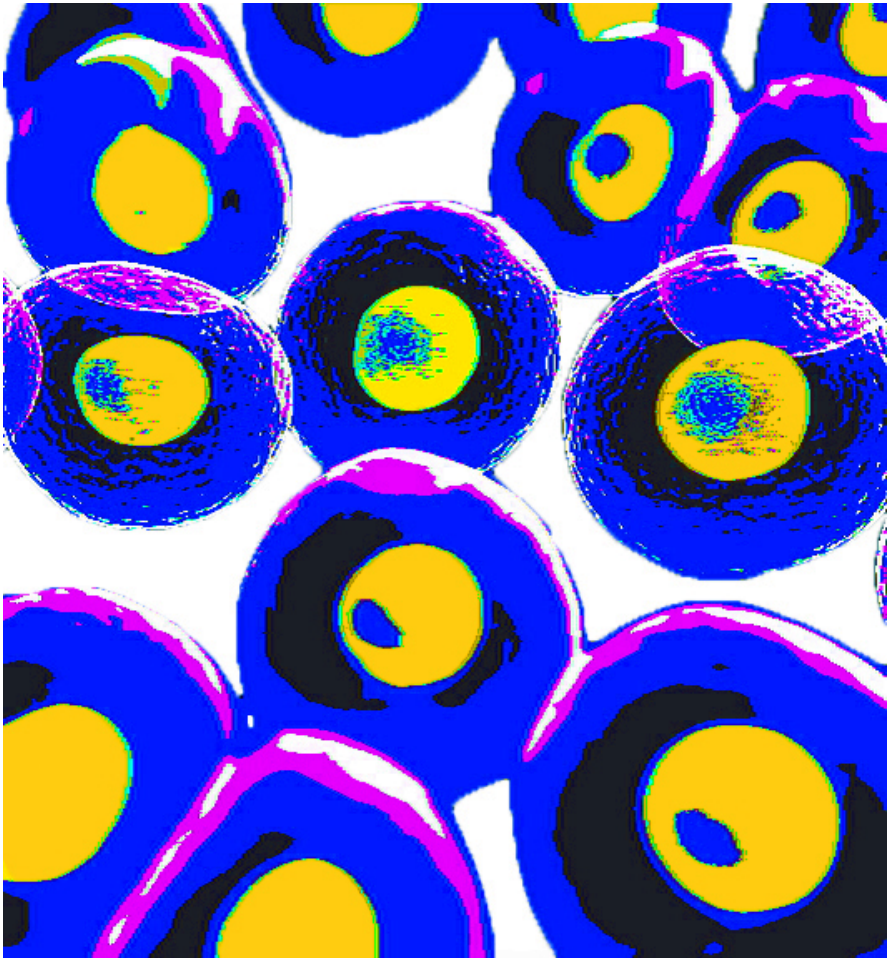


# SEARCH FOR THE HERO INSIDE YOUR CELLS



BY ARABELLA GREVE



For Margot



# Introduction

This is a book about the gift of stem cell donation. It is a set of true stories taken from personal interviews with patients, donors, medical staff, and charity workers involved with the stem cell register.

While researching this book, I realised that - unlike blood and organ donation - very little is known about the amazing advances in stem cell transplantation, and the relatively easy procedure for donating your cells.

The one word used by everyone I interviewed was 'hope.' Recent advancements in medical science and stem cell transplantation have provided exactly that - hope for a future, for patients with blood disorders and cancers which can't be cured with more traditional treatments such as chemotherapy. Unfortunately, there just aren't enough people on the stem cell register to match all the patients who desperately need stem cell transplants. The sad fact of the matter is that people who could be saved are dying.

It is my greatest wish that this book will provide inspiration to young people to sign up to the stem cell register when they become eligible on their 16th birthday. My message, from one teenager to another, is that we have the ability to do something amazing. Our cells are young and healthy, and at no cost to ourselves, we could save someone's life - what greater gift as a human being is there?

At the beginning of the book, I would also like to dispel some of the misconceptions about the procedure for donating stem cells that came up repeatedly while I was researching the topic at school. I want to assure you that the procedure is simple, and

your own health will not be compromised. First of all, registering your tissue-type involves a simple cheek swab which you can do at home, once you receive the kit in the post. Secondly, the most common procedure for donating is similar to giving blood, and usually only takes half a day. Thirdly, we all have millions of stem cells in our blood and they replenish quickly.

I have included a section at the back of the book to explain the science of blood disorders and how stem cell transplants work. There is also a list of websites for the charities and associations that helped me research this book. You can find all the statistics I have used on these websites. These include Anthony Nolan and DKMS UK, where you can register as a donor, as well as access all the information you will need to know before signing up.

In the meantime, please read my interviews with these very inspiring people, and ‘search for the hero inside your cells.’

# The Stem Cell Register

In 1974 Shirley Nolan was desperately trying to find someone who had compatible stem cells with her three-year-old son. He was dying and needed a transplant from an unrelated donor, because there was not a close enough match in his family. Shirley Nolan set up the first ever bone marrow register. This was a list of people who were willing to give their bone marrow (and therefore their stem cells) to save the lives of others: the Anthony Nolan Bone Marrow Register. Though Anthony very sadly couldn't be saved, his legacy was continued by the Anthony Nolan Trust (today, it is simply known as Anthony Nolan) and the bone marrow register set up in his name.

Anthony Nolan's history webpage also tells us that, in 1988, Bone Marrow Donors Worldwide - an aligned register that allowed people to search for a match between 50 registries across the globe - was formed. It is now the World Marrow Donor Association.

In 1991, another charity, DKMS, was set up in Germany by Dr Peter Harf, whose wife had been unable to find a suitable stem cell match. Anthony Nolan's campaigns had all been targeted at potential UK donors. So, according to the history page on their website, DKMS was established to recruit donors in Germany. It is now one of the biggest international donor recruitment charities in the world, with offices in Germany, the UK, Chile, Poland, and the USA.

In 2000 it became possible for people to donate stem cells directly from their blood instead of from their bone marrow, according to Anthony Nolan. Since then, bone marrow registers have become known as stem cell registers.

Today, the World Marrow Donor Association tells us there are over 30 million donors on the aligned register. Unfortunately, the number of available matches still isn't high enough for the many people every year who are left waiting for stem cell transplants.

Matches tend to be found with those of similar ethnic backgrounds. According to a 2018 UK government report, just 15% of the register is made up of people with Black, Asian, or Minority Ethnic (BAME) heritage. In Anthony Nolan's data, they state that people of Northern European descent have a 69% chance of finding a donor with a perfect 'match.' But, if you have BAME heritage, your probability of finding a perfect 'match' drops to just 20%.

Patients are not usually offered stem cell transplants unless there really is no other option. For them, finding a suitable donor is often the only chance of surviving their illness.

Anthony Nolan's statistics show that stem cells from younger donors are more successful in transplants than stem cells from older donors.

By registering, you could save a life.



# Yaser



'I'm a lucky guy. Positive things, good things tend to happen to me. And that left me with a false sense of security because I always believed "it won't ever happen to me".' And then, unfortunately, it did.

In 2013 Yaser and his wife, Vicki, were the parents of two sons, Oscar and Rufus, and a much-longed-for 14-month-old daughter, Margot. She was full of life - but her parents started to notice signs that she was under the weather. 'We didn't know; it broadsided us. Life was going along just peachy, and then suddenly this came along, and bang!' Her naturally pale complexion masked just how ill she had become, and her active nature provided an excuse for the bruises that were appearing on her skin. In fact, by the time the doctors noticed anything was seriously wrong, she was so unwell that she was immediately admitted to the Intensive Care Unit at

Great Ormond Street Children's Hospital. Her blood counts were so far from normal, that doctors initially thought they might have made a mistake with the tests, and re-ran them. Unfortunately, the tests weren't wrong. Margot was dangerously ill with blood cancer. 'I didn't know what Leukaemia was,' Yaser explains, and at that moment, the family's 'world turned upside down.'

The devastating news didn't end there. Within twelve hours of arriving at hospital, the family discovered that Margot had an extremely rare, dual-lineage form of Leukaemia, of which the doctors had only seen three other cases in ten years. It soon became clear that conventional treatment wouldn't be enough - a bone marrow/stem cell transplant was Margot's best, and realistically only, chance of a full recovery.

After learning that Margot's brothers wouldn't be able to provide a suitable match, her parents were told that an unrelated donor would have to be found using the stem cell register. Effectively, this meant searching for a complete stranger who was a 'match' and was willing to donate their stem cells.

To complicate matters further, Margot's family is mixed-race. So, the donor also needed to be of a similar ethnic makeup. Statistically, according to Anthony Nolan, if you are of Northern European heritage and need a stem cell transplant, you have a 69% chance of finding your 'perfect' stem cell match. This drops to just 20% if you're black, Asian, or in an Ethnic Minority. And if like Margot you're mixed-race, this obviously drops even further. Realising the very slim odds of finding a match, Margot's parents felt their only choice was to start campaigning to find a match themselves, in the hope that more people would sign up to the register.

Fortunately, they found a match, and Margot's transplant took

place in February 2014. The transplant was successful, and a couple of months later, she was allowed to go home, having been declared 99% cancer-free.

There were many joyful moments in the next few months as Margot grew from a baby into a fun-loving and energetic toddler who loved tutus, bows and all things pink. The family built lots of happy memories. The stem cell transplant gave Yaser and his family hope for Margot's future once again.

In a letter to Margot's anonymous donor, Yaser wrote, 'You are our hero ... that you thought to take the time to register as a potential stem cell donor and made good on your commitment when our call came, speaks volumes for who you are as a human being.'

Yaser explained to me why he chose to use the word 'hero,' and why the generosity and selflessness of donors should be celebrated. 'Typically, the donor's attitude is, "anyone would have done that," but we know that this simply isn't true.' The stark reality is that, according to Anthony Nolan, just 2% of the UK population is on the register.

Very sadly, Margot's cancer returned in June 2014, and she passed away on 27th October, soon after her second birthday.

Since then, Margot's family have set up a charity in her name, and plan to ensure that every patient - particularly those of mixed heritage - searching for a matching donor can find one. This will become Margot's lasting legacy.

Yaser will always be thankful to Margot's stem cell donor, because, as he has explained, 'we are so grateful for having enjoyed extended time with the family and with loved ones - a priceless gift.'

His final message is, 'a patient only needs one donor, and you could be that donor. Moreover, as is often the case, you might be the only one who can save a life.'



# Chloe



At the age of 23, Chloe read about the stem cell register and the need for more donors through a link on a friend's Facebook page. Already a blood and organ donor, she signed onto Anthony Nolan's register online the same day. 'There was no doubt in my mind that this was something that I wholeheartedly wanted to be involved in.'

Charities running and promoting registers often use the internet to make signing up even easier. All Chloe had to do was fill in an online form with some information, including answers about her general health and contact details. Following this, Anthony Nolan sent her a tissue sample kit. These kits allow people to take a simple cheek swab at home - a five minute process. 'I was so excited for the process of signing up to begin.'

After returning the kit, Chloe's sample was analysed, and her tissue type - which is used to find stem cell matches - identified. Her details were put on the register, and she was now ready to save a life if the call came.

According to Anthony Nolan, the average registrant has just a 1 in 800 chance of being called to donate. Though Chloe was eager to help save a life, she knew that her chances of being called up were slim. So it was a surprise when a few months later, she was contacted by Anthony Nolan - there was someone out there in desperate need of her stem cells. 'When I found out that I was a potential match for someone I was completely overwhelmed.'

Anthony Nolan were very supportive throughout the process. 'There was someone at the end of the phone who advised me through every step of the process, and what I could expect next. I was provided with all the information I would need and the communication was fantastic. They made me feel so comfortable and so important.' Because Chloe had to travel to one of the specialist centres to donate her stem cells, the charity also covered her expenses and the accommodation for her and her mother. Anthony Nolan made the experience as easy as it could be.

Chloe donated her stem cells via Peripheral Blood Stem Cell (PBSC) Collection. This meant some of her blood was removed from one arm and cycled through an apheresis machine, which isolated and removed the stem cells. Her blood was then returned to her other arm. This process - an outpatient procedure which required no anaesthetic - took around four hours. The people around her continued to make her feel comfortable: 'the nurses at the hospital were fantastic and I was also visited by an Anthony Nolan volunteer who answered any other questions that I had. That visit made me feel on top of the world.'

‘I received a letter from the recipient around 8-10 months after the donation. This was - and still is - the best letter I have ever received in my life. Something that was of no real inconvenience to my life had made a world of difference to someone else.’

Chloe now works with Anthony Nolan, campaigning for more people to sign up to the register. ‘To be able to explain to people about the donation process and the impact it can have on someone else is truly phenomenal.’

‘I would go through the process over and over again after knowing the impact it can have.’



# Peter



Peter was diagnosed with Myeloma in 2016. The diagnosis came completely out of the blue. ‘When the doctor sat me down and told me I had cancer, I didn’t believe it. I remember saying “but I’m fitter than I’ve ever been...that can’t be right.”’ Peter is an accomplished triathlete, who has completed the Ironman Challenge - it’s hard to think of a greater test of fitness.

Although Peter has undergone several rounds of chemotherapy and an autologous stem cell transplant (where his own cells were effectively cleaned and returned to his body), doctors have told him that his best chance of survival is a transplant of stem cells from an unrelated donor. Without it, his prognosis is seven years.



Although the World Marrow Donor Association records over 30,000,000 donors registered around the world, none are a close enough match for Peter, and thousands more like him. Or as he sees it, there isn't a match 'yet.' It is with this positive attitude that he has set up a campaign to get 10,000 new donors to sign up to the register, while raising money and awareness. As well as being proactive in finding himself a match, he also aims to help as many other people as he can, and improve the efficiency of the search-and-match process involved. His ultimate goal is that, one day, if someone needs a stem cell transplant, they will have no more trouble finding a match than they would when 'buying aspirin.'

'Every 14 minutes someone gets diagnosed with blood cancer. The technology is there to save them. There just aren't enough people who have signed up to donate their cells.'

Peter is married, and a father to two young sons. Like any father, he desperately wants to see his sons grow up. His situation demonstrates just how much of an impact donating stem cells can have. Not just for the patients, but for their families and loved ones.

With this in mind, I asked Peter if he has a message for teenagers who typically have a sense of invincibility, never giving a second thought to life-threatening conditions such as myeloma. Peter is sympathetic. He clearly remembers being a teenager, and agrees that we are 'invincible' to the extent that we have the power to take control of our lives and steer them in any direction we choose. Our potential seems infinite, but that doesn't mean that we are any less at risk from killer diseases like cancer. 'You have to acknowledge the other side of the coin. We are all human and sadly at some stage in our lives we will face physical frailty.'

‘Right now, each and every human being on the planet has the potential to be a lifesaver at no cost to themselves other than a bit of time. Stem cells are abundant in the body, and the younger you are, the healthier your cells are, so for people like me, younger generations offer great hope of survival.’

Peter also talks about the rewards of ‘giving’ altruistically, and ultimately how we as teenagers can make such a positive impact on the lives of others: ‘as the saying goes, giving a gift is more rewarding than receiving, and to help other human beings is the most rewarding of the lot. Whether you do charitable work, run a cake sale or help an old lady across the road, you will leave a lasting impression on those you help, and those who see you helping. But if you can find it within yourselves, when you’re old enough, to donate stem cells for people, the gift of life is what you are offering. How much more impactful can you be?’

‘No university degree required. You have the power within you. Offer hope to those who need it through nothing more costly than time.’

# Dave



Dave, a police officer, was eighteen when a friend's father invited him to a stem cell registration event for Anthony Nolan. When he understood that by joining the register, he could help save someone's life, he signed up immediately. 'Why would I not agree to that? It was a no-brainer for me.'

When Dave signed up in 2001 he had to take a blood test so that Anthony Nolan could identify his tissue type. Today, however, signing up is as quick and painless as swabbing each side of your mouth for 30 seconds.

Dave's tissue type was kept on the register, and in 2013 he was contacted by Anthony Nolan. A seriously ill teenage girl needed a stem cell transplant, and Dave's cells matched hers.

Dave's stem cells were harvested using Peripheral Blood Stem Cell Donation. He says, 'the donation process was very simple. Anthony Nolan walked me through every step of the way, and while it caused me a small amount of discomfort for

a short period of time, it gave a cancer sufferer more time to spend with their loved ones, and the possibility of one day beating the disease completely.'

Unfortunately, his recipient relapsed the following year, and Dave was called upon to donate a second time. Again, he didn't hesitate to try and help save her life. However, this time he donated through a different method: Bone Marrow Donation. Both DKMS and Anthony Nolan state that only 10% of donors undergo this method of stem cell collection. It is surgical and requires an overnight stay in hospital. During the procedure, bone marrow is collected from the back of the pelvis. This time Dave was under full anaesthetic and felt nothing during the procedure. When he woke up he felt a little bruised, but made a full recovery quickly. Once again, the hope that his stem cells could have saved his recipient's life far outweighed any uncomfortable side-effects.

Very sadly, he was given the news that his recipient had died in February 2015 - her cancer had simply been too aggressive. However, she had been given the invaluable gift of extra time with her family and friends thanks to Dave's generosity and selflessness.

Since then, Dave has worked with Anthony Nolan to convince more people to sign up to the stem cell register and help change lives. 'The one thought that went through my head throughout this process was, "What if it was a member of my family suffering with cancer? There might be someone out there who could potentially save their life, but if they weren't on the register, then they would never know and wouldn't be able to help." For the sake of a few needles and flu like symptoms you could save a life.'

'It is easily the most worthwhile thing I have done, and I would recommend that, if you are physically able, you join the register.'

# Kathryn



Kathryn recently won the 2018 Anthony Nolan Individual Fundraiser of the Year Award.

Kathryn was diagnosed with Acute Myeloid Leukaemia when she was sixteen years old. She started chemotherapy on GCSE Results Day. 'It ended my schooling then, because I was ill for the next three years and disabled after that to the point that A-levels and university weren't really an option.'

On 12th February 2018, Kathryn celebrated 10 years of being in remission - or, as she refers to it, '10 Years of Being Alive'. It's been a long and difficult journey though, and in the intervening years she has endured several rounds of chemotherapy, radiotherapy, countless blood transfusions, stem cell transplants from two separate donors, and a liver transplant. At one point, she was given just a one in five chance of survival.

Her first transplant, on 19th December 2007, came from her sister. Initially her family thought that Kathryn had been cured and would live out the remainder of her life in good health. 'I definitely felt that teenage invincibility thing - I thought I'd have my chemo, have my transplant, be fine in six months.'

Then in April 2008, she realised that lumps were starting to grow on her face; a biopsy confirmed that they were cancerous. Her leukaemia had returned, and this time her chance of survival was just 20%.

Kathryn desperately needed another stem cell transplant and a new donor. Fortunately, a match was found for her on the stem cell register. 'Being of incredibly white Northern European ancestry, the odds of me finding a match from the register were good, and I'm only too aware of how lucky that makes me.'

Though her second transplant was successful, she suffered terrible side effects, the most serious of which was damage to her liver. On Halloween 2008, Kathryn was admitted to hospital, but this time she would spend eight months there. Doctors told her parents that she was unlikely to survive until Christmas without a liver transplant.

She was placed on the waiting-list for a new liver, and on 21st December one became available. It was, however, at a terrible cost to another family. Of all the donors, it was this one that Kathryn tells me she thinks about the most. 'I'm most grateful to the parents of my liver donor. Their daughter was twelve when she got off her school bus and got hit by a van, the week before Christmas. But they wanted her death to not be a waste, and without them I wouldn't have lived to see that Christmas either.'

Against all the odds, Kathryn has survived. Despite the lasting effects of her illness, she now works tirelessly for Anthony Nolan as a Young Ambassador, crediting the charity with not only finding her second stem cell donor, but supporting her through her treatment and its aftermath. 'I tell my story to help champion the vision of Anthony Nolan, as well as raise awareness of their work to other young people, decision makers, and the media.'

'Why should teenagers give? Because unexpected things happen in life. One day you're fine, the next you have cancer. If you needed stem cells, or an organ, or someone you love did, then you would find yourself asking why everyone isn't a donor, when it is so easy and can do so much good?'

# Natasha and Tori



Left: A 2016 promotional poster from Warwick Marrow (source: [persuasion-and-influence.blogspot.com](http://persuasion-and-influence.blogspot.com)); Right: Tori

Anthony Nolan's 2018 data states that only 2% of the UK population was on the stem cell register at the time - just 1.4 million people. To date, those of Caucasian heritage have a 69% chance of finding a life-saving perfect stem cell match from an unrelated donor. Those of black, Asian, or other Minority Ethnic heritage have just a 20% chance. It goes without saying that this is not enough.

However, this number would be far lower if not for the amazing efforts of volunteers for blood cancer charities such as Anthony Nolan and DKMS. One of Anthony Nolan's most important volunteer subgroups is Marrow, which describes itself on its website as a university-based group of students raising awareness and recruiting donors from their community. Marrow groups can be found at universities all around the UK, including Glasgow and Warwick, where Natasha and Tori study.



During her time at university, Natasha joined Glasgow Marrow after seeing an advertisement via email, and went to an Annual General Meeting. This hadn't been her first experience of Anthony Nolan's cause. At the age of eleven, she lived through her father being diagnosed with Leukaemia. 'At the time, I didn't really understand his illness but it was obviously an upsetting time for me and my younger siblings. Since then, we have been lucky that his cancer is able to be treated by medication and he has not yet needed a stem cell transplant.'

Despite this, Natasha's experience has made her realise how much rides on stem cell transplants, not just for the patients, but for their families too. 'My main motivation is that although our family have been "lucky" in not yet needing a stem cell transplant other people are not so blessed. Through my Marrow journey, I have met many people who have lost family and friends to blood cancer and the odds need to change – it is essential that everyone can find a lifesaving match.'

Tori joined Warwick University's Marrow group in 2018, having also felt the repercussions of blood cancer in her family - a young family member died of Leukaemia. Today, she wants to honour her legacy. She also wants to help the 2,000 plus people in the UK alone (according to Anthony Nolan) who need a life-saving stem cell transplant every year. 'It seems to make sense to volunteer and contribute to the growth of the stem cell register when I have such a strong conviction regarding its importance. I would feel useless knowing that so many people are dying from blood cancers when a cure could be out there for them.'

Marrow groups nationwide have been incredibly successful in getting more people to sign up to the stem cell register. Since the foundation of the first group at the University of Nottingham in 1998 - as the Marrow page of Anthony Nolan's website tells us - they have recruited 100,000 new donors! This is largely

due to their monumental efforts, which include everything from donor recruitment drives, to simply going to university events and locations in branded gear.

The Marrow groups also try hard to connect and relate to the university students they target. For Tori and the rest of Warwick Marrow, this means using pop culture references. For example, to capture people's attention, they used posters to turn Dua Lipa's line, 'One kiss is all it takes,' into 'One swab is all it takes!'

Once they have raised awareness, university Marrow groups host recruitment drives. At these, Tori tells me, 'stalls are set up at different locations across the university campus and volunteers explain what stem cell donation is to passers by.' Once they have had the stem cell register explained to them, students often choose to sign up, and are lead through the swabbing process at the stall. Five minutes later, the students have signed up to the stem cell register, and from that moment on, effectively have the potential to save a life.

One of the main hurdles that Natasha, Tori, and other Marrow volunteers are faced with is dispelling the misconceptions related to the stem cell register. 'I was most shocked that a medic thought we would be extracting his bone marrow there and then!' Natasha tells me. One of the most common misconceptions is that stem cell donation is painful, when - at most - it only ever causes minor discomfort. As Natasha explains, 'when I am talking to students I always lead with the line "Do you want to save a life?" which usually stops people, as they don't understand what I mean. Speaking to stem cell donors, they most commonly say it's similar to the side effects of a gym session – you can feel slightly achy and tired. But your achiness means that another family have hope that their loved one could survive blood cancer, and that is something so special.'

I asked Natasha why she thought teenagers should sign up to the stem cell register. She told me, 'it's important that teenagers care for several reasons. First of all, anyone can be affected by blood cancer. Every 14 minutes, someone in the UK is diagnosed with blood cancer and many patients do go on to require a stem cell transplant. Teenagers should sign up when they are eligible because younger donors are better donors. Young, healthy donors give people with blood cancer a better chance of survival. Other than this simple statistic, donating stem cells is such a truly selfless thing to do. Imagine being able to save someone's life and have an impact on that person's family, friends, work colleagues, simply by donating your stem cells?'

# Alex



Seventeen-year-old Alex has recently signed up to the stem cell register. He is fit, active, and a talented skateboarder who has competed all over the world. He is also mixed race. This means that if he became ill and needed a stem cell transplant to save his life, he would have a very slim chance of finding a match. He shares this statistic with the 13% of the UK population who have Black, Asian, Minority Ethnic (BAME), or mixed backgrounds, according to the UK government's 'Ethnicity in the UK' webpage.

It was purely by chance that Alex had seen a campaign on social media for a young cancer sufferer who desperately needed a stem cell transplant, and it really hit home. He began to imagine a scenario where his younger sister fell ill and needed a transplant. 'The thought of that is devastating - it would completely change my life. Then I realised that the maths is simple. The more people there are on the register, the greater her chance would be of finding a match.

That is the thought that motivated me to sign up.'

'My message to other teenagers is that it's pretty easy to sign up. If everyone knew how simple it was, a lot more people would be on the register.'

Registering with either Anthony Nolan or DKMS, as Alex found out, only requires you to read some information and confirm you don't have any medical conditions that might put you or the patient in danger, if they were to receive your stem cells. Then you have to provide some simple information, including your name and contact details. The charity that you choose to sign up with will send you a swab kit, which takes five minutes to complete. It is as simple as rubbing a cotton bud on the inside of each cheek for 30 seconds.

The fact that Alex saw an appeal by chance highlights just how many people are held back from saving lives due to lack of awareness. 'It's shocking to me that people are dying simply because others don't know about the register.' It's so important that people know the facts from an early age, so that they are ready to sign up as soon as they become eligible.

According to Anthony Nolan, the average registrant has just a 1 in 800 chance of being called up. However, for men between 16 and 30, this rises to a 1 in 200 chance. Alex knows that his chances of being asked to donate are slim. 'But,' he adds, 'I really hope I am called up. I can't think of anything more rewarding than saving someone's life.'

# Jackie

I spoke to Jackie Horder, Stem Cell Clinical Nurse Specialist at University College London Hospital, to get an idea of what's involved in stem cell donation, and what donors can expect once they have been identified as a match.

Her first message is very positive: 'Donating stem cells is much simpler than it sounds!'

Once a donor is called up, they will be asked to undergo a medical examination, and will have to answer questions about their health and travel history. This is because the transplant team has to make sure that potential donors are fit enough and suitable to donate. The procedure will be explained in detail, so that the donor completely understands what's involved. There are two different ways that stem cells can be donated, and donors are usually asked if they have a preference:

1. The most common is the Peripheral Stem Cell Harvest, which is a similar procedure to giving blood. 'Your blood is drawn through a machine that separates it into different layers. The layer containing the stem cells is collected in a bag and the rest of your blood simply flows back into you. It isn't painful – just a bit boring as it takes around 5 hours.' She also explains that donors shouldn't experience any side-effects, and should be able to get back to their normal activities straight afterwards.
2. The second, more 'traditional' method - which is now only used 10% of the time, according to Anthony Nolan - is Bone Marrow Harvesting. This method requires a general

anaesthetic, so that stem cells can be drawn from the back of the hip bone. 'The bone marrow harvest is actually nothing like as painful as you might think as you will be fast asleep.'

'Both methods have the same end result – you give someone a second chance at life! It may not ultimately save them, as some diseases are just too aggressive to be cured. But you are doing the most amazing thing that anyone can do for someone else, and you may never be able to make such an enormous difference to anyone again.'

# The Science

Many people suffer from debilitating and potentially life-threatening illnesses. These are often caused by problems with their blood or immune systems. For a long time many of these conditions were death sentences. Some still can't be cured but the advances in medicine today help patients to live longer, more comfortable lives.

Better-known conditions include blood cancers such as Leukaemia and Lymphoma. Other lesser-known ones include Thalassaemia.

Our blood is made up of red blood cells which carry oxygen through the body, white blood cells which are part of the immune system, and platelets which clot the blood and stop us from bleeding to death. All these cells develop from stem cells in our bone marrow. According to the NHS, there are more than 70 conditions that can be treated with stem cell transplants. These include:

**Leukaemia** - A blood cancer where faulty DNA that has formed in white blood cells causes them to grow and divide too rapidly. These cells - which also cannot perform their primary role of fighting diseases - begin to overcrowd other cells in the blood. This means that there aren't enough red blood cells, normal white blood cells, and platelets to perform their vital jobs in the body. This is what makes Leukaemia so dangerous.

**Lymphoma** - A blood cancer where lymphocytes (a type of white blood cell which is part of the lymphatic system, used to fight off infections) grow and divide too quickly. The faulty lymphocytes overcrowd the other cells in the blood, preventing them from functioning. These faulty lymphocytes can travel



throughout the lymphatic system (which stretches across the body), and eventually gather together to form lumps. These usually start forming at the lymph nodes in the back of the neck, but can also be found elsewhere in the body since the faulty cells can spread.

**Myeloma** - A blood cancer where a type of Lymphocyte, which usually matures into a plasma cell, develops faulty DNA during its transformation. The DNA causes the cell to reproduce rapidly, crowding the bone marrow so that it cannot produce enough other blood cells. It is currently almost impossible to cure. At the moment, stem cell transplants from donors are very unusual for myeloma patients, but they present the only hope of survival.

**Severe Aplastic Anaemia** - A group of anaemias where the bone marrow doesn't produce enough of any type of blood cell, preventing each from carrying out their vital role. It is usually caused by an autoimmune reaction where the immune system thinks the bone marrow is defective and attacks it, stopping it from producing enough blood cells. A bone marrow transplant is the only cure.

**Sickle Cell Disease** - A group of congenital, lifelong, genetic conditions. Sickle Cell sufferers are born without enough healthy red blood cells in their bodies. Instead, these red blood cells are rigid and shaped like sickles, so they can't properly carry oxygen around the body. They can often become lodged in blood vessels, limiting the blood flow and oxygen supply to certain parts of the body. This can result in very painful episodes called crises, and often carries the risk of severe complications, including strokes. People of African, Middle Eastern, Caribbean, Asian, and Eastern Mediterranean descent are much more likely to be born with the condition.

**Thalassaemia** - A group of lifelong conditions where the bone marrow produces abnormal, very little, or no haemoglobin (the part of the red blood cell which carries oxygen). This leads to a deficiency in red blood cells, known as anaemia. It is triggered by a gene inherited from a patient's parents, and mainly affects people of Mediterranean, Middle Eastern, Southeast Asian, and South Asian heritage.

**Myelodysplastic Syndromes (MDS)** - A group of disorders where the bone marrow produces too many blood cells which don't work. The ones that are produced are defective and immature, and often don't survive once they leave the bone marrow. Furthermore, they crowd out the healthy blood cells in the bone marrow so that very few go through the bloodstream. It can sometimes develop into a form of Leukaemia.

There are many different treatments for blood disorders, and these include stem cell transplants. In the case of Sickle Cell Disease, Myeloma, Thalassaemia, Severe Aplastic Anaemia, and MDS, stem cell transplantation is the only treatment which can cure a patient.

## Stem Cells

A stem cell can transform into many different types of cell. Unlike nerve cells or red blood cells, which are adapted to perform a specific function, stem cells are not specialised. One stem cell can also produce thousands more stem cells with the same properties. All our cells are built from them.

There are many stem cells in the bone marrow, which differentiate into red and white blood cells, as well as platelets. Therefore, if stem cells were taken from the bone marrow, they would have the potential to generate these more specific cells wherever they were placed after extraction. This is the idea with a stem cell transplant.

## Stem Cell Transplants

In a stem cell transplant, stem cells are extracted from the blood or bone marrow and transplanted into someone else's bloodstream. Often patients will undergo intense chemotherapy and sometimes radiotherapy before a transplant. This is called conditioning therapy. Chemotherapy doses are higher and more toxic in this treatment than in traditional chemotherapy treatments. This is so that the source of the problem in the patient's blood can be killed off. In Leukaemia, for example, this treatment kills all the mutated, cancerous white blood cells. Once the stem cells are implanted, they create healthy versions of all the cells that were killed. This means that the patient can soon develop a brand-new, completely healthy set of blood cells, and a working immune system.

## The Process of Stem Cell Donation

Being a stem cell donor is a relatively simple process. Once a donor is called upon, and they are found to be the best possible match for a patient, they will be invited to undergo some simple health checks.

Next, the donor process will be explained. There are two methods of collection: in the first, the donor receives some injections of a naturally-occurring growth hormone in the four days leading up to the procedure. These help make more stem cells grow, so that as many as possible can be collected. After these injections, which can be administered at home by a local nurse, the donor will be invited to a specialist centre. Blood will be drawn out from one arm, and passed through a machine called an apheresis. This separates the blood into different layers, removes the stem cells, and collects them in a bag. The remainder of your blood simply flows back through the other arm. According to Anthony Nolan, this method is used 90% of the time.

In the second method of collection, a general anaesthetic is used at hospital, and bone marrow is taken from the back of the pelvis. The stem cells are then collected from the extracted bone marrow.

In both procedures, DKMS notes that a tiny proportion of the total stem cells in the blood are extracted. A courier takes the bone marrow/stem cells to the patient, who will have the transplant within 72 hours.

## Donor Matches

Patients in need of a stem cell transplant have to find a 'matching' donor. This relates to HLA tissue typing. HLA (Human Leukocyte Antigen) markers are proteins found on the surface of the cells in our body, and can be tested through a blood sample. The immune system uses these markers to detect whether cells belong inside the body or whether they are foreign. Usually, foreign cells - which have different sets of HLA markers - are hostile and can make us ill. This means that when the immune system detects a set of markers that isn't usually found within the body, it immediately assumes that the body is under attack. It is important therefore, that any 'good' foreign cells transplanted into the body (such as stem cells) have similar HLA markers. If this weren't the case, the donor's immune cells would recognise the patient's own cells as foreign and attack them. This is called Graft vs Host Disease, and can be life-threatening to a patient.

Doctors will usually try to find as close a match as possible to prevent Graft vs Host from happening. If a patient has any siblings, they will be tested first. This is because half of a person's HLA markers are inherited from their mother and half from their father. According to Anthony Nolan, there is a 25% chance that a sibling will be a 'perfect' match. In other words, there's a roughly one in four chance that the ten HLA markers

that scientists test from a sibling's blood sample will be identical to the ten HLA markers they test from the patient's. However, if this match does not materialise, then it is necessary to find an unrelated donor whose HLA markers match as closely as possible. Most acceptable matches are upwards of 8/10, and 10/10 matches are known as 'perfect matches.'

There are some circumstances where lower matches are used. For example, if there is a chance that any faulty cells could survive the conditioning therapy, doctors may want Graft vs Host to take place. This would allow the new immune system to attack the remaining faulty cells, but would require a lower match. Additionally, if no suitable match can be found, it is sometimes necessary to try transplanting stem cells with a lower HLA compatibility.

Most people find matches from their own ethnic background. This makes it vitally important that more people from Black, Asian, Minority Ethnic, and mixed-race communities sign up to the stem cell register. The reason for this is that, at present, there are so few BAME people on the register that if someone from one of these communities needed a stem cell transplant, their chances of finding a perfect match would only be 20% (according to the charity Anthony Nolan). This would drop even further for those of mixed heritage (according to Dr Daniel McCloskey, an HLA matching specialist, previously at the Clinical Transplantation Laboratory at the Royal London Hospital). This compares to a 69% chance of finding a perfect match for someone of white Northern European heritage.

# Resources

## Where to Sign Up

Anthony Nolan

<https://www.anthonynolan.org/>

Anthony Nolan accepts stem cell donors between the ages of 16 and 30. It also has very good information about the register and all aspects of the donation process.

DKMS UK

<https://www.dkms.org.uk/en>

DKMS UK accepts stem cell donors between the ages of 17 and 55. Like Anthony Nolan, it will answer any questions you have about stem cell donation and the register.

The British Bone Marrow Registry

<https://www.nhsbt.nhs.uk/british-bone-marrow-registry/>

This NHS-run stem cell register allows blood donors between the ages of 17 and 40 to become stem cell donors alongside by testing a small sample of donated blood. Male donors can be of any ethnicity, but female donors must have BAME or mixed heritage.

## Useful Sources

Search for the Hero Inside Your Cells Instagram

[https://www.instagram.com/the\\_hero\\_inside\\_your\\_cells/?hl=en](https://www.instagram.com/the_hero_inside_your_cells/?hl=en)

A teenage-run Instagram page raising awareness, promoting patient appeals to find donors, and providing news on the stem cell community. Follow the link or scan the nametag at the back of the book.

## Team Margot

<http://www.teammargot.com/>

A signpost charity co-run by the Martini family (see Yaser Martini's interview on page 5), set up in order to recruit more donors - especially those of BAME heritage - to the register. Its namesake, Margot Martini, became the subject of an incredible stem cell donor recruitment campaign following her diagnosis of an extremely rare form of Leukaemia at the age of just 14 months.

## 10,000 Donors

<http://10000donors.com/>

The site of a new - and already successful - campaign set up by Myeloma patient Peter McCleave to recruit 10,000 new stem cell donors to the register. See Peter's interview on page 12.

## ACLT

<https://aclt.org/about-us/>

A stem cell charity which helps sign up more donors, and focuses on encouraging more members of BAME communities to join the register. It was set up by the family of the first black individual to have a stem cell transplant from an unrelated donor.

## Riprap - Stem Cell Transplants

[http://www.riprap.org.uk/knowledge/cancer\\_treatment/stem\\_cell\\_transplants.asp](http://www.riprap.org.uk/knowledge/cancer_treatment/stem_cell_transplants.asp)

A charity which supports the children of cancer sufferers. Its page on stem cell transplants is very well-explained and easy to understand.

## Macmillan Cancer Support - Stem Cell and Bone Marrow Transplants

<https://www.macmillan.org.uk/information-and-support/treating/stem-cell-and-bone-marrow-transplants>

A very easy to understand, comprehensive explanation of the science behind stem cell transplants, as well as what they involve from a patient standpoint.

## ‘Ending the Silent Crisis’ UK Government 2018 Report

<http://www.nbta-uk.org.uk/wp-content/uploads/2018/06/BAME-Donation-review-29.5.18.pdf>

A UK government report (lead by Eleanor Smith MP) investigating the shortage of blood, organ, and stem cell donors from BAME communities. It suggests reasons for this BAME donor shortage - sometimes known as the ‘silent crisis’ - as well as possible solutions.

## UK Government - Ethnicity in the UK

<https://www.ethnicity-facts-figures.service.gov.uk/ethnicity-in-the-uk>

Information on the ethnic backgrounds and diversity in the UK population.

## NHS - Stem Cell and Bone Marrow Transplants

<https://www.nhs.uk/conditions/stem-cell-transplant/>

The UK government’s official, detailed explanation of how stem cell transplants work, why they are carried out, and what they involve. The page is aimed at patients but also includes useful information about stem cells in general.



## Cancer Research UK - About Graft Versus Host Disease (GvHD)

<https://www.cancerresearchuk.org/about-cancer/coping/physically/gvhd/about>

A comprehensive and readable explanation of Graft versus Host Disease. It was originally aimed at patients, but is also really useful for anyone trying to understand the complicated issue.

## Anthony Nolan - Quick Links

‘Our History’: <https://www.anthonynolan.org/about-us/our-history>

‘Facts and Stats’: <https://www.anthonynolan.org/facts-and-stats>

‘Marrow’: <https://www.anthonynolan.org/8-ways-you-could-save-life/volunteer-us/marrow/who-we-are>

‘2018 State of the Registry Report’: [https://www.anthonynolan.org/sites/default/files/2018\\_State\\_Of\\_The\\_Registry\\_2017%20data.pdf](https://www.anthonynolan.org/sites/default/files/2018_State_Of_The_Registry_2017%20data.pdf)

‘Leukaemia’: <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-blood-cancer#Leukaemia>

‘Lymphoma’: <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-blood-cancer#Lymphoma>

‘Myeloma’: <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-blood-cancer/myeloma>

‘Severe Aplastic Anaemia’: <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-blood-disorder/aplastic-anaemia>

‘Sickle Cell Disease’: <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-blood-disorder/sickle-cell-diseases-scd>

‘Thalassaemia’: <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-blood-disorder/thalassaemia>

‘Myelodysplastic Syndromes’: <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-blood-disorder/myelodysplastic-syndrome>

‘Frequently Asked Questions’: <https://www.anthonynolan.org/frequently-asked-questions>

## DKMS UK - Quick Links

‘About Us’: <https://www.dkms.org.uk/en/content/about-dkms>

‘From Registration to Donation: The Process Explained’: <https://www.dkms.org.uk/en/registration-donation-process-explained>

‘Frequently Asked Questions’: <https://www.dkms.org.uk/en/frequently-asked-questions>

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‘It is our choices... that show  
what we truly are, far more than  
our abilities.’ - J.K. Rowling





‘We have the ability to do something amazing. Our cells are young and healthy, and at no cost to ourselves, we could save someone’s life - what greater gift as a human being is there?’

‘You are doing the most amazing thing that anyone can do for someone else, and you may never be able to make such an enormous difference to anyone again.’

‘If you can find it within yourselves, when you’re old enough, to donate stem cells for people, the gift of life is what you are offering. How much more impactful can you be?’

