ABMDR
Australian Bone Marrow Donor Registry

AUSTRALIAN BONE MARROW DONOR REGISTRY

2017–2018

CHAIR'S WELCOME

The Australian Bone Marrow Donor Registry serves all Australian patients who need an unrelated haemopoietic stem cell transplant. It is our job to find each patient the best available donor match.

Transplants from younger male donors are generally the most ideal. This is because many female donors develop antibodies during pregnancy which can cause rejection in a transplant recipient. We also need to identify any viruses carried by the donor. Cytomegalovirus, for example, causes a minor illness in most people but can be a serious problem for those with a suppressed immune system.

Other important variables include what type of donation is available: bone marrow, peripheral blood stem cells or stored cord blood stem cells. Finally, we consider where the donor cells are coming from. Australian transplant programs have shown just as strong results if the cells are brought here from overseas instead of being collected locally; however, the cost and logistics differ in each case.

Added together, each of these factors illustrates the need for an Australian Bone Marrow Donor Registry that can provide as many ideal donors as possible. We are therefore devising better ways to recruit and test donors for the registry, which we are discussing with federal and state governments.

Our comprehensive online database helps patients and their families examine the various donor options that are available. During a recent change to our systems, hospital staff, laboratories and the search coordination centres collaborated amazingly well with our dedicated IS team. We now have a much more stable and secure suite of programs as a result.

This year, the Australian Bone Marrow Donor Registry searched on behalf of more people than ever before. We helped hundreds of Australians and their families find that needle in a haystack – the best matched donor. We all remain in awe of the bravery and determination that drives each and every one of them.

Jeremy Chapman
Chair

EXECUTIVE'S WELCOME

The 2017–18 year has been a turning point for the Australian Bone Marrow Donor Registry.

We have worked closely with federal and state governments, as well as independent reviewers, to define a better structural and funding approach to bone marrow donor recruitment in Australia. This is critically important. Having the right donors available in Australia gives patients the best chance of a successful transplant. It also provides the best value for the nation's health expenditure.

Children represent a significant share of the people the registry helps every year. In this Annual Report, we offer the inspiring stories of Hunter and Henry, showcasing their extraordinary courage to overcome serious illness at a very young age. Our donor story is by Daniel, who was inspired to join the registry after his two-year-old niece received a life-saving transplant. The registry is very grateful to Hunter and Henry and their families for sharing their experiences and reminding the Australian public of the importance of the donations that we facilitate. Thank you as well to Daniel, not only for your story, but for being so willing to donate to a complete stranger.

The Australian Bone Marrow Donor Registry manages and coordinates the search for the best donor or cord blood unit for patients who require a bone marrow transplant. We exist for the patients, and provide services to many groups in the community to make this happen. In 2017–18, we have consolidated all aspects of how we work, including risk management, financial processes and information systems, to fulfil our mission more effectively.

We look forward to working with governments over the next 12 months to implement further changes to donor recruitment to provide an even better service for our patients.

Anthony Montague
National Executive Officer

2017–18 AT A GLANCE

There are about

170,000 donors

on the Australian Bone Marrow Donor Registry

1,553 new cord blood units

were made available for transplant, including 82 cord blood units from Indigenous donors

787 Australian patients

accessed the registry to search for an unrelated donor

6,658 donors

were retired from the registry at age 60

40%

of new donors who joined the registry are of a background other than North-West European, adding valuable diversity

About

33 million donors

and 750,000 cord blood units are available worldwide

ABOUT US

Who we are

The Australian Bone Marrow Donor Registry is a public company limited by guarantee and a registered charity under the Australian Charities and Not-for-profits Commission.

It is the organisation responsible for recruiting volunteer bone marrow/blood stem cell donors and managing the administration of the National Cord Blood Collection Network of public cord blood banks in Australia.

The Australian Bone Marrow Donor Registry, including cord blood operations, is funded by the Commonwealth, State and Territory governments through a variety of funding agreements.

Where we are

The Australian Bone Marrow Donor Registry's National Office is based in Sydney where the staff work closely with the Australian Red Cross Blood Service. A wider network of bone marrow donor centres and other facilities (see below) is located in the state capital cities and also serves metropolitan and country areas in Australia.

The National Cord Blood Collection Network (AusCord) cord blood banks and collection centres are located in Sydney, Melbourne and Brisbane. There is also an Indigenous collection centre in Darwin.

Who we help

The Australian Bone Marrow Donor Registry helps Australian and international patients who are in need of a stem cell transplant and have not found a donor among their relatives. Volunteer bone marrow donors and umbilical cord blood donors who are willing to help any person in the world in need of a transplant are welcome to join the registry.

Our network

The Australian Bone Marrow Donor Registry relies on a nationwide network to help patients and donors.

- **Australian Red Cross Blood Service bone marrow donor centres:** the donor centres are responsible for managing the list of available donors. This includes recruitment, counselling and advocacy for donors at all stages of the donation process.
- **Tissue typing laboratories:** these provide human leukocyte antigen (HLA) typing services for patients and donors. This includes expert advice on tissue typing matters, as well as a dedicated search coordinator to manage searches on behalf of patients requiring family and unrelated donor searches.
- **Transplant centres:** the transplant centres provide transplant services for Australian patients needing bone marrow transplantation. They care for the patients and initiate the search for suitably matched donors through the Australian Bone Marrow Donor Registry via local search coordinators.
- **Collection and apheresis centres:** the collection and apheresis centres collect the blood stem cells from the volunteer Australian Bone Marrow Donor Registry donors prior to transplant. In collaboration with the donor centres, the staff members counsel donors before collection, perform a physical assessment and look after the donor's welfare.
- **AusCord cord blood banks:** AusCord cord blood banks manage the donation of umbilical cord blood units. They counsel the volunteer mothers, collect, process, store and release cord blood units for public use. The cord blood banks operate within a strict Therapeutics Goods Administration (TGA) regulatory framework.

FAST FACTS

What is bone marrow and who needs it?

Bone marrow is the spongy tissue found inside bones. Bone marrow in the breast bone, skull, hips, ribs and spine contain stem cells that produce the body's blood cells. These blood cells include:

- white blood cells, which fight disease and infection
- red blood cells, which carry oxygen
- platelets, which enable the blood to clot.

Bone marrow transplant is an accepted treatment for patients diagnosed with leukaemia and certain immune system and genetic disorders.

What is involved in the donation process?

There are two methods for donating stem cells: extracting them from bone marrow under general anaesthetic and collecting them from the circulating bloodstream. Each method involves different risks. If you are chosen to donate stem cells for a patient, you will be asked to visit a medical specialist who will conduct a detailed check of your fitness to donate. In Australia, donations occur in the major hospitals in the capital cities. The Australian Bone Marrow Donor Registry will cover all medical and hospital expenses relating to the stem cell donation, including incidental costs. These include the costs of travelling to and from hospital, and accommodation, if necessary. The main cost to you as a donor will be your time.

Thinking about donating?

If you live in Australia, are aged between 18 and 45, meet the eligibility criteria – including being in good health – and are prepared to donate for anyone in the world, call the Australian Red Cross Blood Service on 131 495 to make an appointment.

For more information about the donation process, please read our brochure Joining the Bone Marrow Registry, which is available at any Australian Red Cross Blood Service Donor Centre or from the registry's website (**https://www.abmdr.org.au/**). For answers to frequently asked questions, visit **https://www.abmdr.org.au/faq/**.

CONTACT YOUR DONOR CENTRE

Western Australia

Australian Red Cross Blood Service
Email: bmdcwa@redcrossblood.org.au
Phone: +61 8 9421 2323
Fax: +61 8 9325 4115

Queensland

Australian Red Cross Blood Service
Email: bmdcqld@redcrossblood.org.au
Phone: +61 7 3838 9019
Fax: +61 7 3838 9407

South Australia and Northern Territory

Women's and Children's Hospital
Email: bmdcsa@redcrossblood.org.au
Phone: +61 8 8422 1242
Fax: +61 8 8422 1293

Victoria and Tasmania

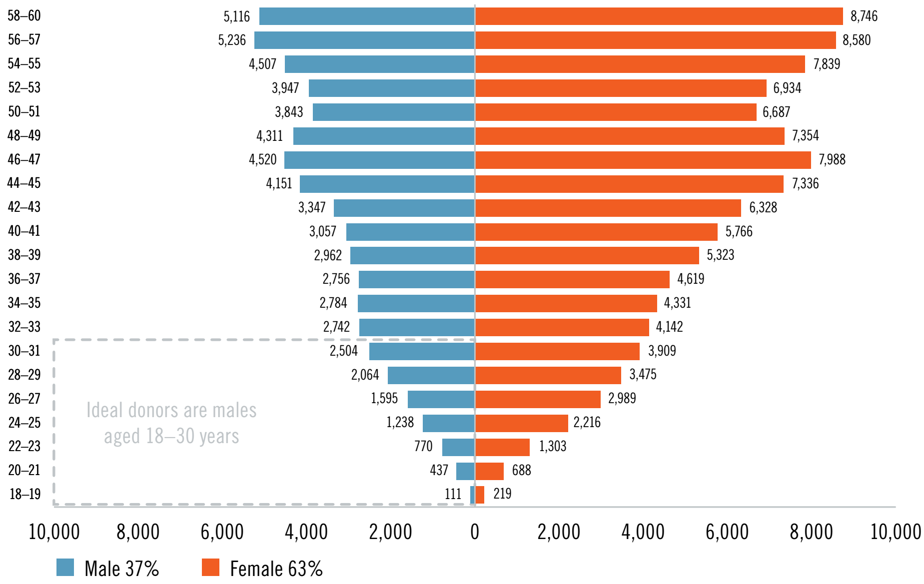
Australian Red Cross Blood Service
Email: bmdcvictas@redcrossblood.org.au
Phone: +61 3 9694 0101
Fax: +61 3 9328 8232

New South Wales and Australian Capital Territory

Australian Red Cross Blood Service
Email: bmdcnswact@redcrossblood.org.au
Phone: +61 2 9234 2354
Fax: +61 2 9234 2362

REGISTRY ACTIVITY

Donors on the registry as at 30 June 2018

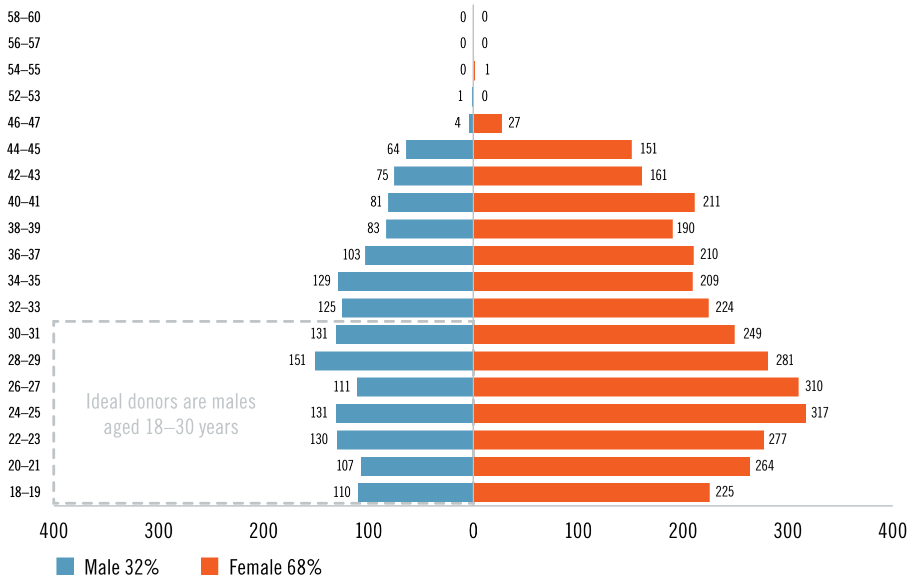


There are

168,770 donors

on the registry, of which 4% are males aged between 18 and 30 (these are ideal donors).

New donors joining the registry in 2017–18

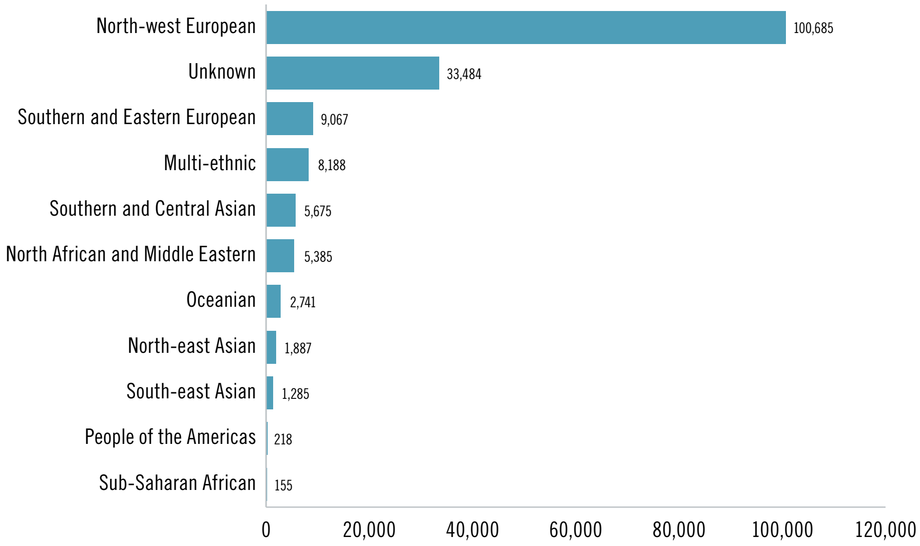


A total of

4,843 new donors

joined the registry, with ideal donors comprising 17% of new donors.

Donor ethnicity as at 30 June 2018*



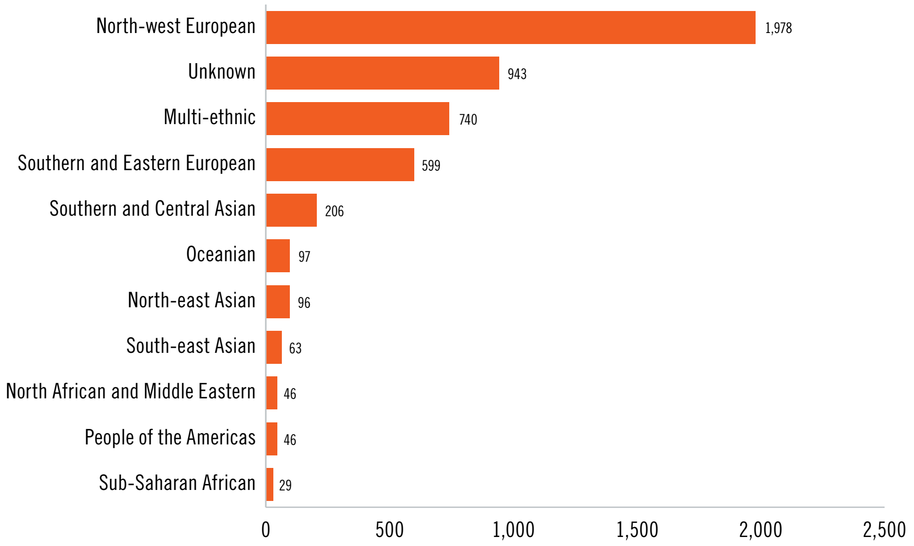
* Ethnicity is categorised using the *Australian Standard Classification of Cultural and Ethnic Groups* (ASCCEG) 2016, Australian Bureau of Statics cat. no. 1249.0. Canberra: ABS.

A total of

21%

of donors on the registry are of a background other than North-West European, or have multiple ethnicities.

Ethnicity of new donors joining the registry in 2017–18*



* Ethnicity is categorised using the *Australian Standard Classification of Cultural and Ethnic Groups* (ASCCEG) 2016, Australian Bureau of Statics cat. no. 1249.0. Canberra: ABS.

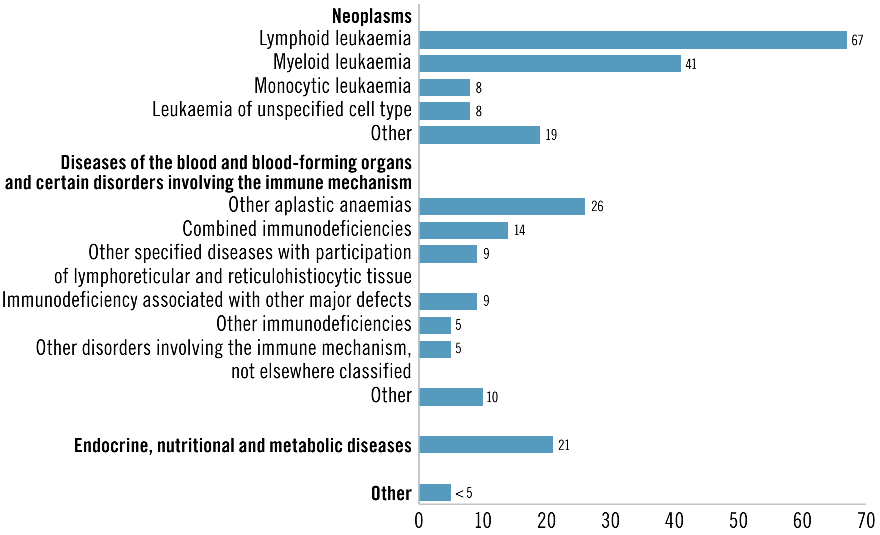
In 2017–18,

40%

of new donors who joined the registry were of a background other than North-West European, or have multiple ethnicities.

REGISTRY ACTIVITY

Australian paediatric patients receiving an unrelated transplant, by diagnosis 1 July 2013 to 30 June 2018



* Patients aged 0 to 15 years

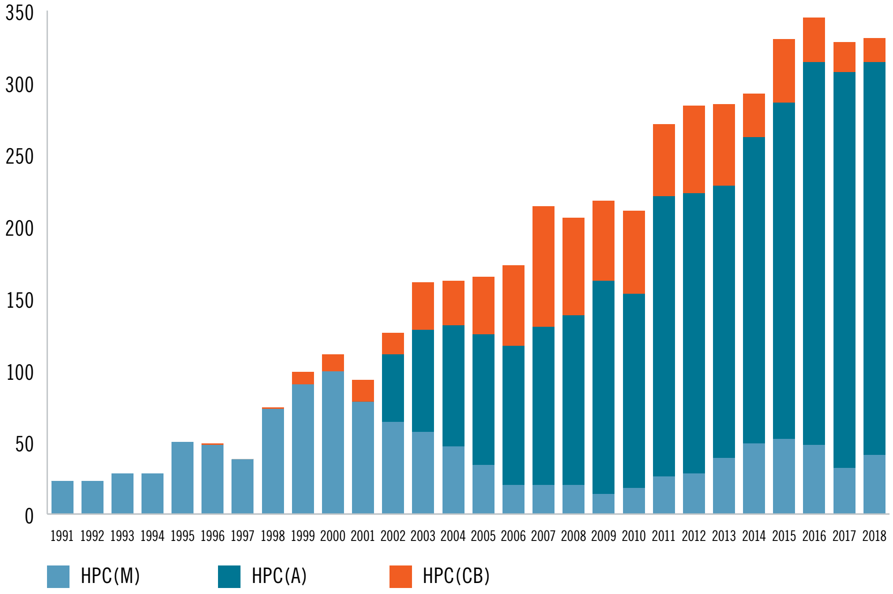
Approximately

250

Australian patients aged between 0 and 15 received an unrelated transplant during the last five years.

More than half of the paediatric recipients had a malignant neoplasm of lymphoid, haemopoietic and related tissue; and more than one-third had a disease of the blood and blood-forming organs, as well as certain immune system disorders.

Australian patients receiving an unrelated transplant, by donation type 1 July 1991 to 30 June 2018

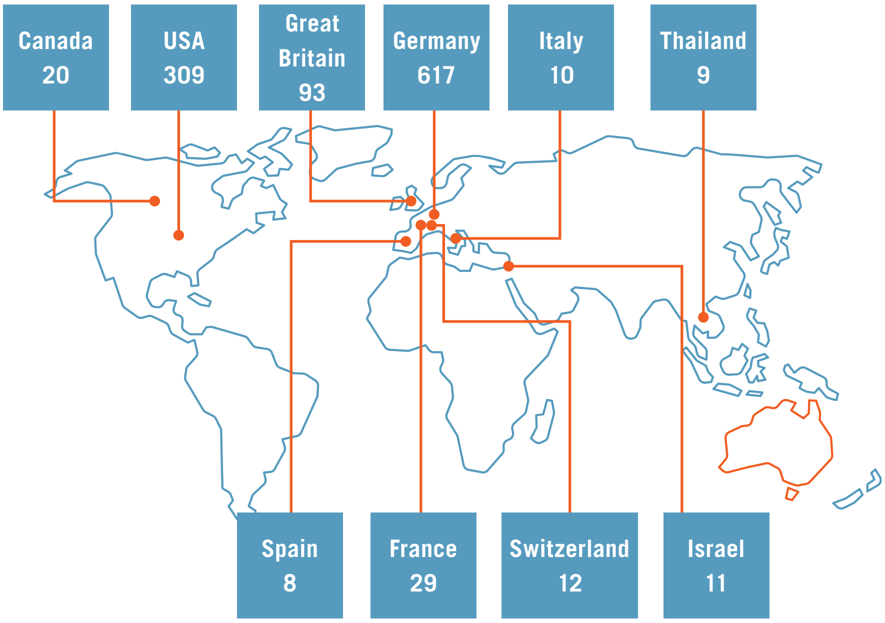


A total of

331

Australian patients received an unrelated transplant in 2017–18, of which 82% were recipients of haemopoietic progenitor cell apheresis HPC(A), 12% were recipients of HPC(M) (through bone marrow extraction) and 5% were recipients of HPC(CB) (through cord blood).

Australian reliance on HPC imports from 1 July 2013 to 30 June 2018

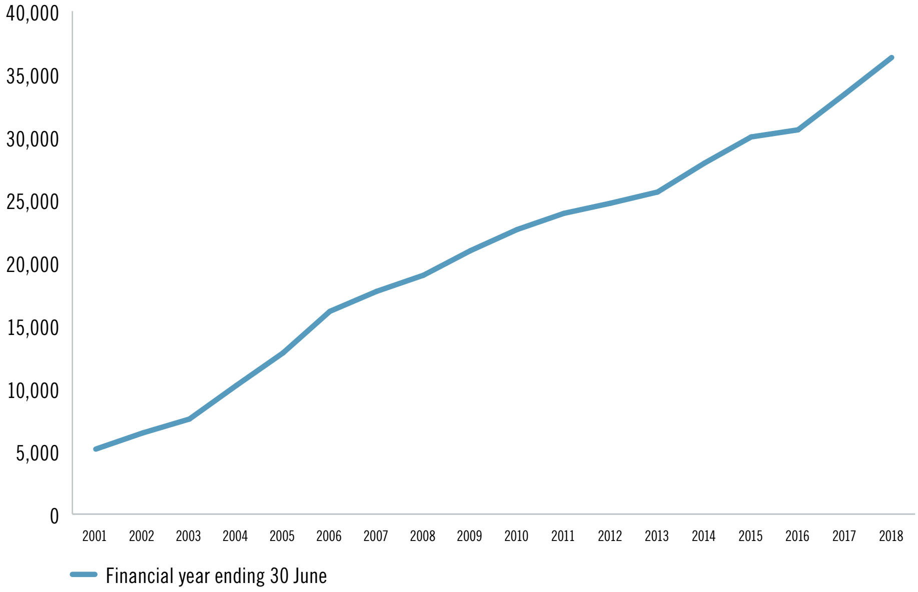


Germany has provided

617 HPC donations

and the United States has provided 309 HPC donations for Australian transplants over the last five years.

Searchable Australian cord blood units (cumulative)



There were

36,306

searchable Australian cord blood units as at 30 June 2018.

DANIEL’S STORY

“To be honest
with you, it
was one of the
most humbling,
pay-it-forward
moments you
could possibly
have.”

Daniel was inspired to become a bone marrow donor after watching another person's generosity perform a miracle for his two-year-old niece.

Daniel will always remember the day in December 2017 he agreed to donate his bone marrow to save a little boy's life. *"I'm tough as nails, played lots of footy; I can't remember crying like that ever before,"* he says. *"Even talking about it now brings tears to my eyes. I'll never forget that phone call to say I was a match for someone."*

For the 43-year-old, who lives in Warrnambool on Victoria's Great Ocean Road, the decision to donate bone marrow was a no-brainer. Just three years earlier, he had witnessed the generosity of another donor keep his niece alive.

Remy, the daughter of Daniel's brother, was diagnosed with aplastic anaemia in December 2014. She was just two at the time. *"I was playing with Remy; we were running around the kitchen, I was pretending to be a horse and she was on my back and all the rest of it,"* Daniel remembers. *"The following day, she ended up with a heap of bruises, and people thought I'd just been a little bit rough with her on my back. She went to the doctors for a check-up and blood test. That's how we found out that her bone marrow was failing."*

After doing some research, Daniel and several other family members opted to go on the Australian Bone Marrow Donor Registry. They also spread the word among their social circles, and on Facebook. However, when nobody turned out to be a match for Remy's bone marrow, Daniel's brother was beside himself with anxiety.

To make matters worse, the condition of Remy – by now relocated to the Royal Children's Hospital in Melbourne – was rapidly deteriorating. Declining platelet levels required her to have blood transfusions every seven to 10 days. *"When you have a bone marrow failure, it's obviously very serious,"* Daniel says. *"The blood transfusions were the only thing keeping her alive. It was so hard not being able to control the situation. Bone marrow failure is probably one of those diseases that if you don't get onto it straight away, you won't be here."*

The family's relief was overwhelming when an unrelated donor match was found, allowing the brave toddler to have the transplant procedure in January 2015. The road since hasn't been easy. However, Remy, now six, is back at school, her immune system is improving every day and she is leading a relatively normal life.

Relieved by Remy's narrow escape, Daniel stayed on the register despite not being a bone marrow match for his niece, knowing there was only a remote chance he would be contacted. Three years later, he received a call informing him that he had been matched. While the rules of the Australian Bone Marrow Donor Registry preclude the identity of transplant recipients being disclosed, Daniel was told his bone marrow was desperately needed by a five-year-old boy. Adding to the sense of fate, the boy had aplastic anaemia – the same as Remy. *"To be honest with you, it was one of the most humbling, pay-it-forward moments you could possibly have,"* he says.

"Somebody random gave my niece new life. For me to be able to do the same thing – and especially to hear that it was also a child – was absolutely amazing."

Daniel's donation took place at Royal Melbourne Hospital following a series of blood tests and X-rays to confirm he was healthy. He wore a special purple AFL top into the operating theatre. It's the same stripe that St Kilda wear in their annual game with Richmond in honour of Maddie Riewoldt, who died from aplastic anaemia in 2015 and was the sister of player Nick Riewoldt. *"You sit on the bed waiting for them to take the bone marrow out of your body,"* Daniel says. *"The little bit of pain that I endured after the procedure was absolutely nothing compared to what the recipient was going through."*

Donating blood has a much higher profile in Australia than donating bone marrow. Daniel admits that if he had known about the registry, he would have signed up 20 years ago. He believes that everyone should be on the register, and more work needs to be done to recruit young males.

Bone marrow donors gain the satisfaction of knowing they are making a difference during their lifetime. *"Most times when you help someone by donating an organ, you're probably not here yourself, because you're donating an organ that you need,"* Daniel explains. *"To actually be alive and to save someone else's life, I don't know how else I could feel that sense of achievement in all the things I've ever done, and all that I'll do in the future.*

"My advice to all the young people out there is to get on the register, because you can really make a difference to someone's life."

HUNTER’S STORY

“Hunter’s got a second chance at life because someone’s been able to take a small amount of time out of their day”

When Hunter was diagnosed with a rare form of blood cancer, and the chemotherapy stopped working, his family's last hope was a bone marrow transplant.

Hunter was an active and cheeky boy – enjoying football and basketball just like all the other schoolkids. But on the eve of a family trip to Southeast Asia last year, his mother Jacqui noticed something wrong. Her son had big lumps on his neck. As an oncology nurse, she pointed it out to a GP straight away but was told that everything was normal.

The family went on their holiday – enjoying Legoland Malaysia and Universal Studios in Singapore. Looking back, Jacqui is glad they did because life quickly became a rollercoaster upon their return.

Pressing doctors for answers as to why lymph nodes were still showing, Hunter was sent to the Royal Children's Hospital in Melbourne. Following blood and genetic testing, he was diagnosed with a rare form of blood cancer called early T-cell precursor (ETP) lymphoma, and immediately started induction and consolidation chemotherapy. The family was also tested to find a potential bone marrow match, in anticipation that Hunter would need a transplant. *"ETP is a very poor-prognosis blood cancer,"* Jacqui says. *"Even with maintenance chemo, the chance of him relapsing was going to be quite high. We expected at some point he would need to have a bone marrow transplant – we just didn't know when it was going to happen."*

For months, Jacqui and her husband managed the stress of shuttling between home and Melbourne – a three-hour drive away – taking turns to spend weeks at Hunter's bedside. When her husband had to return home to work full time, Jacqui took up a solo vigil. Their younger son was still attending school and it was important to retain some semblance of routine. For his part, Hunter was no longer able to walk, and was riddled with infections. *"Hunter just got on with it,"* Jacqui says. *"He was extremely sick, he had no option and did what had to be done. He put up with procedures and horrible things that kids shouldn't have to go through. I'm very proud of how he's dealt with the last 12 months."*

Five months after Hunter's diagnosis, doctors confirmed the chemotherapy was no longer working – meaning a bone marrow transplant was unavoidable. The Australian Bone Marrow Donor Registry was engaged as nobody in the family was a match. Hunter's parents also put out feelers to their local networks. No suitable donor in Australia could be found, forcing one to be sourced through an international registry. *"The process felt smooth but I'm sure it wasn't as easy as we perceived it,"* Jacqui says. *"A lot of people worked in the background to make it happen."*

The transplant procedure took place two months later. Hunter was in the transplant unit for 39 days. On day 30, the family snuck his brother inside for a quick visit, allowing a lovely reunion between the long-separated boys. Hunter also underwent twice-daily total body irradiation.

Still susceptible to infection, Hunter had to remain isolated and within one hour of the hospital for 100 days. As soon as his remission was confirmed, he went home and resumed school. He's in a wheelchair part of the time, active in Paralympic sports, and otherwise healthy. Gradually, he's gaining the strength to get up and walk.

To this day, his mother is filled with gratitude to the donor. *"Hunter's got a second chance at life because someone's been able to take a small amount of time out of their day and basically donate blood,"* she says. *"They don't have to go through an invasive procedure to have it done."*

Jacqui encourages more people to put their names on the registry, greatly increasing the chances of matches for patients who are seriously ill. *"We would have so many donors to choose from. That would be the ultimate goal, for the government to get behind it,"* she says.

Above all, the family's experiences have taught them that life is precious. *"You appreciate things so much more,"* Jacqui says. *"Even though the weather's been freezing cold, it's nice to be outside and enjoy the beautiful spring air. Hunter's got a better appreciation for how good things are – particularly when they can be really, really bad."*

HENRY'S STORY

“He’s a fighter. He never lost his sense of humour and that’s what got him through.”

Brotherly love and an incredible zest for life helped Henry survive the ordeal of not one, but two bone marrow transplants.

One bone marrow transplant is more than any child should endure. To have two by the age of 10 might seem especially cruel. Yet aided by an extraordinary will to survive, and a family prepared to sacrifice everything, young Henry typifies the meaning of courage.

Henry grew up in the suburbs of Brisbane, one of four rambunctious brothers. *"They fight like cats and dogs, but they've got each other's backs,"* says his mother Bridget proudly. Diagnosed with leukaemia in February 2013 at age seven, Henry started chemotherapy. Within months, it was clear the treatment wasn't working and the only remaining option was to receive a bone marrow transplant. The youngest of his brothers, four-year-old Finlay, was a perfect match. So in August 2013, Henry received Finlay's donor cells at the Royal Children's Hospital in Brisbane (later renamed Lady Cilento Children's Hospital).

The procedure didn't kill all traces of cancer. However, doctors were able to take advantage of an immune response known as graft-versus-tumour (GVT) effect, essentially using the donor cells to eradicate the remaining leukaemia cells. This was successful, and Henry was in complete remission by December.

Life returned to normal until mid-2016. *"Henry had been fine – a pretty healthy, active kid,"* Bridget remembers. *"One night, he just said to me that he was feeling tired and his heart felt like it was racing. I immediately had this feeling of dread. I thought to myself, 'That doesn't sound right', so I took him for a full blood test."*

The family was on holiday on the Gold Coast when Henry's oncologist rang to say the cancer had returned and Henry would need to be back in Brisbane at 6am the next morning. Again, Henry required a bone marrow transplant, chemotherapy and blood transfusions. Doctors felt his chances of survival this time were better with a donor who was not a family member. *"Finlay was really upset when Henry relapsed,"* Bridget says. *"He was worried that he had failed. And so, we had to really let Finlay know that it had nothing to do with him. His cells did an amazing job. It was just that Henry's cancer was so bad and naughty."*

Several matches for Henry's bone marrow were found on the Australian Bone Marrow Donor Registry. The first potential donor decided not to proceed; fortunately, another quickly stepped up. Bridget remembers that the build-up to the transplant was very emotional, unlike the first time when her son was too young to understand his condition's seriousness. Bravely, Henry was also helping to raise awareness through the Children's Hospital Foundation and Humpty Dumpty Foundation.

"Henry knew this time that his cancer had returned," she says. *"He would do talks in public about his journey to help fundraise. And that was hard because he would cry. There were days when he'd ask me, 'Is everything going to be ok?' And you'd try – you don't want to lie to your kid – but you've got to have your confident face on all the time, which for a parent is exhausting.*

"The second time around, Henry's chances of survival were quite low, but we don't focus on the numbers because he's proven us wrong every step of the way. He's a fighter. He never lost his sense of humour and that's what got him through."

Henry's bone marrow transplant took place in September 2016. The cells were donated early in the morning, arriving at Brisbane that afternoon. Afterwards, Henry's parents attended their son's hospital bedside for weeks, waiting for the donor cells to grow inside his body. Bridget is particularly thankful for the support of her mother-in-law and Henry's school. Many friends, looking for ways to help, also took her advice to donate blood and get on the Australian Bone Marrow Donor Registry. *"Whenever there's a child involved, people come together and as awful as it sounds, this brought so many people together,"* she says.

Henry was forced to skip Year 2 and Year 5, instead studying catch-up lessons in hospital. He is now in high school and is gradually getting back into sports; his check-ups have been reduced to one every six months and he no longer takes medication. *"I think of all my children, the one who would deal with this best was always going to be him,"* Bridget says. *"But it's made all of us more resilient. We don't know life without cancer. This year's the first one where we've been able to breathe. We're like a normal family with normal stresses now, which is really lovely."*

The family has a dual perspective, as bone marrow donor and recipient. Bridget recalls with wonder Finlay's sacrifice as a four-year-old to provide Henry's first transplant. *"What an amazing thing for Finlay to do,"* she says. *"To this day, he knows he has done something so special and for the rest of his life, he can hold his head proud."*

While urging more Australians to join the registry, she is understanding of the potential donor who changed her mind at the last minute. *"I was that mother who was just desperate for her son to survive. I wanted that perfect match. I was so emotional, just so devastated when I heard she'd said 'No'. But that lasted two minutes because I turned around and thought, 'You know what, I totally get it. It's not a light decision'."*

As for the person who ended up donating to Henry? *"I think about them every day. They don't realise they've created so much happiness in our life. What they've done – it's so huge. It's such an amazing thing, and I wish more people would do it."*

AUSCORD CORD BLOOD BANKS REPORT

Australia's network of cord blood banks have improved their ability to serve bone marrow transplant recipients this year, reports Chair Dr Robyn Rodwell

A new operational era begins

The AusCord network of cord blood banks entered a new era on 3 July 2017. As part of a project funded by the Australian Government, many crucial operational processes were aligned that will benefit patients requiring manufactured haemopoietic progenitor cell (HPC) cord blood. This is an essential therapy that is used in bone marrow transplant procedures.

Specifically, the cord blood banks have improved their ability to produce high-quality, red blood cell and plasma-reduced standard product (approximately 30 millilitres in volume) in single cryobags. Having a lower product volume will benefit bone marrow transplant patients as there will be fewer red blood cells and less cryoprotectant used to protect cells during freezing. This will reduce the risk of adverse events occurring during the blood infusion. It is also more cost-effective.

This major project was successfully completed within budget, achieving all benefits outlined in the business plan. Robust, multi-centre validation studies were performed. The manufacture of cord blood was also streamlined. From an information technology perspective, submitting a single technical master file to the Therapeutic Goods Administration (TGA) facilitated a simpler review and approval process. Overall, these achievements establish a platform for ongoing improvement and a successful model for other countries wishing to transform cord blood banking.

Among other benefits, the blood banks can now:

- make decisions nationally rather than on an individual basis about replacing equipment, changing protocols and designing multi centre validation studies
- present a unified approach to regulatory authorities
- access a national register of suppliers and service providers
- perform risk assessment and allocate supplier audits at a national level, creating efficiencies for both blood banks and suppliers.

Cord blood

remains an important transplant source for patients without a matched donor.

The

AusCord cord blood banks

manage the donation of umbilical cord blood units; they also counsel volunteer mothers, and collect, process, store and release cord blood units for public use.

AusCord had a repository of

36,306

frozen cord blood units as of 30 June 2018.

A total of

1,312 units

have been released as potential life-saving therapy for patients requiring a stem cell transplant.

We wish to acknowledge a large and dedicated team at the Australian Bone Marrow Donor Registry and the cord blood banks, led by Professor Jeremy Chapman as Chair of the Cord Blood National Management Committee, which contributed to different aspects of the project.

Active on the world stage

AusCord senior members continued to be actively engaged at an international level in 2017–18. This fosters valuable links between Australia and global industry partners and regulatory bodies. AusCord is represented on the Board of the Foundation for the Accreditation of Cellular Therapy (FACT). It is also a member of the steering committee and sub-committees developing the 7th Edition of the NetCord-FACT International Cord Blood Standards, participates in FACT's quality management, accreditation and education committees, and provides expertise for FACT inspections.

Acknowledgement of Dr Karin Tiedemann OAM

Dr Karin Tiedemann, the founding Medical Director of the Bone Marrow Donor Institute (BMDI) Cord Blood Bank in Melbourne, has announced she will shortly retire. Karin has played a pioneering role in both paediatric transplantation and cord blood banking in Australia. She will leave a wonderful legacy and trail of achievements.

Karin is a leader and mentor to many people in both the medical and scientific sectors. She has worked tirelessly with medical directors in Sydney and Brisbane to develop common medical/family history questionnaires and guidelines for selecting mothers and cord blood donors. She has also generously shared her knowledge and time in researching clinical risks that face the industry.

Karin's enormous contribution in the field has been justly recognised with a Medal of the Order of Australia. Her wise counsel and friendship will be greatly missed.

BONE MARROW DONOR CENTRES REPORT

Australia's Bone Marrow Donor Centres are engaged in a campaign to diversify the donor registry, reports National Operations Manager Paul Berghofer

Australia's

Bone Marrow Donor Centres

(BMDCs) work closely with the Australian Bone Marrow Donor Registry.

They look after donor recruitment and enquiries, organise blood samples and tissue typing, and coordinate the process for medical review and donation. They also provide

counselling to donors

before and after donation.

There are

five BMDCs

in Australia covering every state and territory: New South Wales/Australian Capital Territory, Victoria/Tasmania, South Australia/Northern Territory, Queensland and Western Australia.

The past 12 months have been a period of progress and growth for Australia's Bone Marrow Donor Centres (BMDCs). A key part of our work is targeting donor recruitment. For example, feedback from the Australian Bone Marrow Donor Registry's consultations with transplant physicians, and a review of past records reveal the most ideal donors to be young males.

In addition, a patient is most likely to match with a donor from the same ethnic background. This is because patients and donors are matched by human leukocyte antigen (HLA) type. As HLA is a wholly inherited trait, it follows that the best way to meet the needs of an increasingly diverse patient population is to build a panel of volunteer donors that mirrors this diversity. In summary, there is a clear need to increase the representation of young, ethnically diverse males on the registry.

This year, the BMDCs have worked closely with the Australian Red Cross Blood Service donor centres to recruit donors to the Australian Bone Marrow Donor Registry that align with this strategy. This is important as approximately 80% of recruitment is done through the blood donor centres. Twenty-nine educational presentations were made by the BMDCs to blood donor centre staff members throughout the year. These efforts have been further supported by structural changes within the Australian Red Cross Blood Service, notably the transition of the BMDCs into the Donor Services Division of the organisation.

The BMDCs also raised awareness of bone marrow donation by conducting 12 additional educational presentations in the wider community, seeking to encourage more healthy, young and ethnically diverse males to join the registry.

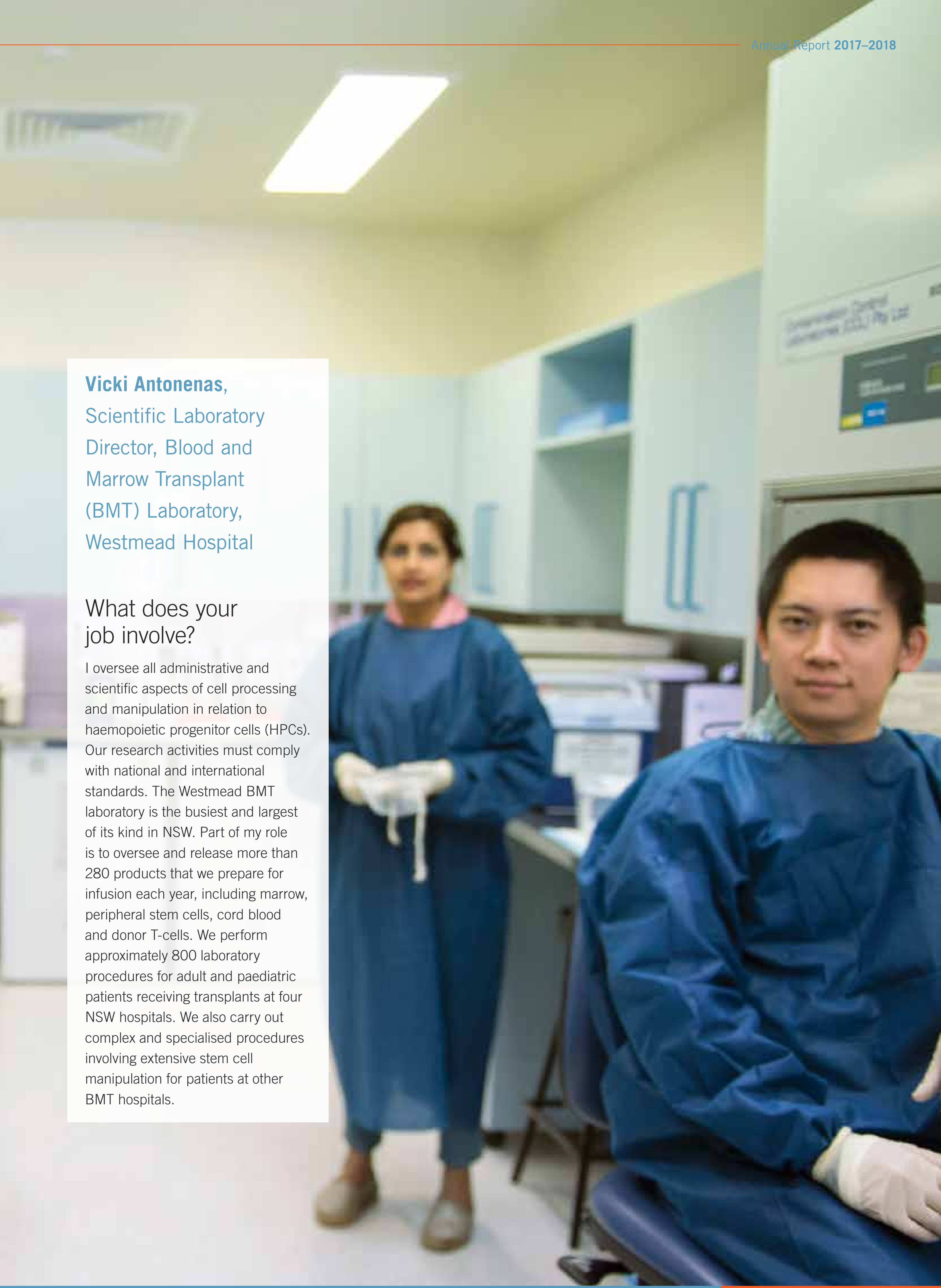
During 2017–18, the average age of donors recruited was 31. This compares with an average recruitment age of up to 33 in previous years, indicating progress towards attracting more donors aged under 30. To enhance the ethnic diversity of the donor registry, 12 recruitment drives were held around the country. Many involved collaboration with members of Australia's Sri Lankan, Indian, Jewish and Aboriginal communities.

Executing this strategy has not been without challenges. As mentioned, the majority of recruitment to the Australian Bone Marrow Donor Registry is done through blood donor centres at the time of a blood donation. The current panel of 170,000 donors simply would not exist without the relationship between the Blood Service and the registry. In Australia, however, the typical first-time blood donor is a female of North-West European ethnicity, so the progress that has been made to preferentially target ethnically diverse young male donors should not be taken lightly.

The goal now is to reduce the average age of recruited donors to under 30 years, and also ensure greater ethnic diversity. Almost 80% of donors who are currently on the registry report that they are of North-West European ethnicity. Most other ethnic groups are still underrepresented.

The BMDCs now have a strong platform from which to achieve these goals. Over the next 12 months, we look forward to exciting new initiatives to improve outcomes for Australian patients.

A DAY IN THE LIFE



Vicki Antonenas, Scientific Laboratory Director, Blood and Marrow Transplant (BMT) Laboratory, Westmead Hospital

What does your job involve?

I oversee all administrative and scientific aspects of cell processing and manipulation in relation to haemopoietic progenitor cells (HPCs). Our research activities must comply with national and international standards. The Westmead BMT laboratory is the busiest and largest of its kind in NSW. Part of my role is to oversee and release more than 280 products that we prepare for infusion each year, including marrow, peripheral stem cells, cord blood and donor T-cells. We perform approximately 800 laboratory procedures for adult and paediatric patients receiving transplants at four NSW hospitals. We also carry out complex and specialised procedures involving extensive stem cell manipulation for patients at other BMT hospitals.

Are there other aspects to your job?

I am involved in national and international laboratory inspections for the National Association of Testing Authorities and the Foundation for the Accreditation of Cellular Therapy.

How long have you been in this role?

Twenty-four years. During this time, I have developed strong collaborations with fellow BMT units and friendships with many Australian and overseas colleagues. I am interested in improving, teaching and advancing all cell procedures for BMT and cellular therapy.

I work with an incredible team. Everyone is so dedicated, which is probably why I have been at Westmead Hospital for so many years.

How did you come to work as a BMT scientist?

Before joining the BMT laboratory, I worked in Westmead's Leukaemia Research Department for 10 years. I also completed my Master of Science in Medicine with the assistance of Professor Kenneth Bradstock who was head of the BMT Program at Westmead Hospital. I took on the BMT lab role as research, which was (and still is today) supported by grant money. I always wanted to work in a lab in the fight against cancer, so I guess I have been successful in my choice of career.

What is a typical day like for you?

Today, for example, we have cells collected from three adult patients at other hospitals for their own future use (a process known as an autologous transplant). These cells need to be processed and frozen and the lab is responsible for transporting them. We expect an overseas product to arrive later, coordinated by the Australian Bone Marrow Donor Registry, which we will process further in the lab before infusion. We also have two products to release today for infusions. My team receives and releases frozen chimeric antigen receptor (CAR) T cells, which are used to treat aggressive leukaemia. Overall, our workload is increasing and we are in the process of seeking more scientists.

What skills do you and other staff require to facilitate a successful transplant?

The major skill we rely on is extreme aseptic cell processing techniques. The processing of cells has to be done cleanly to avoid contamination when infused back into patients. Extreme attention to detail is also required when completing paperwork – ensuring accurate clinical information, requests, medical record numbers and details of all testing. The job requires clear communication, learning quickly and handling stress when things sometimes don't go according to plan.

What support do you receive from the Australian Bone Marrow Donor Registry?

I have worked very closely with the registry for many years. We are in constant communication regarding products collected from interstate or overseas, including transport and courier arrangements. We also give feedback regarding test results and problematic issues, including low viability and inadequate cell doses.

How busy does it get performing transplants?

Very busy. Our BMT lab provides a full-time service to four BMT hospitals in NSW. It is also the referral lab for all donor bone marrow collected at Westmead Hospital that is not related to the registry. Over the last 18 months, we have been directly involved in distributing CAR T-cells and immune effector cells (IECs), which are T-cells that target the most common infections that occur following transplantation.

How many transplants are carried out monthly?

In June 2018, our lab carried out 82 procedures. These included processing 23 incoming products; performing 21 HPC infusions, seven IEC and CAR T-cell infusions, and four complex cell procedures; and testing and processing 27 other products.

What do you find most fulfilling about your role?

Working as a team and making a significant difference in providing high-quality and safe BMT laboratory services for our patients. I love the constant clinical interaction and guidance from the BMT transplant physicians, nurses, coordinators and apheresis collectors, but most importantly, I enjoy working with my own staff. I like implementing new cell technologies in my lab and seeing my team fly. We've been able to provide a higher quality graft to our BMT patients, reducing infusion time and the chance of an adverse reaction.

What are some of your biggest challenges?

The challenges include increased paperwork requirements and validations, the demanding regulations and standards thrown at us, implementing new label systems (such as ISBT 128, a global standard) and introducing new cellular therapies with IEC and CAR T-cells. Our lab is performing at the level associated with international accreditation. We're also introducing new cell processing machines to reduce time-consuming, complex procedures if possible.

What's your vision for the future?

The next five years will be very exciting for the BMT field. I foresee our patients benefiting from new therapies or specific cell-targeted therapies, either provided by specialists in Australia or by big companies operating globally. The increase in cellular therapeutic products like CAR T-cells will offer better clinical outcomes for BMT patients (and other solid cancers). From a laboratory point of view, I see greater use of automated cell processing machines for fast, clean and consistent products. We currently have the first such machine in an Australian lab and are excited about its many applications.

ABMDR BOARD

Professor Jeremy Chapman AC – Chair

Professor Jeremy Chapman is Clinical Director of Medicine and Cancer at Westmead Hospital, and Director of Western Renal Services. He is also Deputy Chair of the Western Sydney Local Health District Board.

Jeremy has been involved with the tissue typing laboratories and the Australian organ donation program for the past 30 years. He has chaired the Board of the Australian Bone Marrow Donor Registry since its creation in 1991.

Jeremy's current interests include conducting research and teaching at the University of Sydney. He is Editor in Chief of the journals Transplantation and Transplantation Direct.

Associate Professor Peter Bardy

Associate Professor Peter Bardy trained in clinical, laboratory and research haematology at the Institute of Medical and Veterinary Science, then at Vancouver General Hospital and Terry Fox Laboratory in Vancouver, Canada.

His first consultant position was as a clinical haematologist in Royal Melbourne Hospital's Leukaemia and Bone Marrow Transplantation service, from 1995 to 1997. After returning to Adelaide, he held positions at the Australian Red Cross Blood Service, Royal Adelaide Hospital and The Queen Elizabeth Hospital.

Since 2005, Peter has held various leadership roles in the public health sector, including as Medical Head of the Division of Medicine at The Queen Elizabeth Hospital, Chief Medical Officer in the Central Northern Adelaide Health Service, Chair of the South Australian Clinical Senate, Interim Clinical Director of the Cancer Centre at Royal Adelaide Hospital, and Clinical Director of Cancer Services in the Central Adelaide Local Health Network. He also chairs South Australia's Blood Management Council.

Brian Farmer

Brian is a bone marrow donor who donated in 1993, and was a member of the registry's Ethics Committee. An engineer by training and a project manager by profession, Brian is a Churchill Fellow, has been Chairman of the Sydney University International House Council, and was Chairman of Standards Australia's Contracts Committee, which produced the AS2124/AS4000 suites of contracts. He is also a past Managing Director of Capital Insight Pty Ltd.

Sally Gordon

Sally Gordon is a registered nurse who for 28 years worked in the field of transplantation, specialising in solid organ, tissue and bone marrow donation. During that time, she was one of two state organ donor coordinators at the Australian Red Cross Blood Service's Transfusion Service, and was seconded to the NSW Department of Health on a project investigating the feasibility of a state-wide tissue banking service. In 1991, Sally was appointed as the Australian Bone Marrow Donor Registry's inaugural Executive Officer. She retired from this position in 2013 but remains on the National Management Board.

Greg Wilkie

Greg Wilkie, who joined the board on 28 March 2018, is the Executive Director of Manufacturing and Quality at the Australian Red Cross Blood Service. He has experience leading operational teams and establishing the service's National Contact Centre in Adelaide. He has also recently driven actions to establish a lean continuous improvement culture within the service's manufacturing business.

Before joining the Australian Red Cross Blood Service, Greg focused predominantly on business improvement and customer service operations within the logistics, transport and energy industries. This includes his time as Transfers Operations Manager at AGL Energy and various leadership roles with Royal Mail in the United Kingdom.

Anthony Montague

Anthony Montague is the National Executive Officer of the Australian Bone Marrow Donor Registry. Before taking on this role, he was the National Cord Blood Network Operations Manager, a role he held for eight years. Anthony originally trained as an engineer, and he has 25 years' experience in development, quality systems, project management and business management. In the last 10 years, he has directed his attention to healthcare management, in particular bone marrow transplantation and the systems for delivering health information. His qualifications include a Bachelor of Engineer (Honours) and a Master of Public Health from the University of Sydney, and a Master of Business Administration (Executive) from the Australian Graduate School of Management.

ABMDR BOARD

Professor John Croucher AM

Professor John Croucher, who retired from the board on 21 January 2018, has been an outstanding figure in the higher education sector for many years, playing a significant role nationally and internationally. He received the prestigious inaugural Distinguished Alumni Award from Macquarie University for his exceptional achievements both locally and abroad, and his outstanding contributions to the mathematics and statistics professions. In January 2015, John was made a Member of the Order of Australia (AM) for 'significant service to mathematical science in the field of statistics, as an academic, author and mentor and to professional organisations'.

John has won more national learning and teaching awards than any other academic in the country, and in 2013 he received the prestigious Prime Minister's Award for Australian University Teacher of the Year. As a leading researcher, he has published more than 120 refereed research journal articles and 25 refereed conference papers in areas of interest to educators, statisticians, lawyers, medical practitioners, mathematicians, computer analysts, historians, scientists and managers. Of these articles and papers, 70% appeared in international journals published in Asia, New Zealand, the United States and the United Kingdom.

John is also one of Australia's most prolific authors, having published 30 books both in Australia and abroad. He is an elected Fellow of the Royal South Australian Society of Arts and the Australian Mathematical Society, and his world-class research has led to numerous invitations as a keynote speaker before local and international audiences. He is also currently a professor in the Macquarie Graduate School of Management at Macquarie University.

In March 2013, John was diagnosed with Acute Myeloid Leukaemia (AML) and in 2015 underwent a bone marrow transplant from an unrelated donor. The transplant was very successful, thanks largely to the wonderful work of John's medical team and the Australian Bone Marrow Donor Registry. As a result, John brings a uniquely personal perspective to the Board.

Professor Jeff Szer AM

Jeff was the foundation Director and a professor at The Royal Melbourne Hospital's Department of Clinical Haematology & Bone Marrow Transplant service until August 2016, when his Department integrated with the Peter MacCallum Cancer Centre Haematology Department. He continues as a Disease Group Lead in Clinical Haematology at PeterMac and The Royal Melbourne Hospital and is a professor at the University of Melbourne's Faculty of Medicine, Dentistry and Health Sciences.

He was also the foundation President of the Bone Marrow Transplant Society of Australia and New Zealand, and remains a member of the Steering Committee for the Australasian Bone Marrow Transplant Recipient Registry. Jeff is the immediate past President of the Worldwide Network for Blood and Marrow Transplantation and President-Elect of the World Marrow Donor Association. He is also a member of the Advisory Committee of the Center for International Blood and Marrow Transplant Research.

Jeff is Editor in Chief of the Internal Medicine Journal and a member of the editorial boards of the Bone Marrow Transplantation, Blood Reviews, Blood Cell Therapy and BioMed Central journals. He has published more than 300 papers in the field of marrow transplantation and blood disorders.

Leonie Walsh

Leonie Walsh is an experienced leader and adviser in technological innovation with a background that spans more than 30 years of local and global experience across many industries. Leonie continues to focus on strategic science and technology issues – including innovation efficiency, technology commercialisation, the future skilled workforce and women in science – through a range of related board, advisory and advocacy activities.

In addition to Leonie's role as Non-Executive Director of the Australian Bone Marrow Donor Registry, she is President and Chair of the Fight Cancer Foundation, as well as a board member and Co-chair of the Patient Advisory and Advocacy Committee for the Worldwide Network for Blood and Marrow Transplantation.

Leonie recently completed a three-year term as Victoria's inaugural Lead Scientist. In this capacity, she was a contributing member on the Future Industries Ministerial Advisory Council; contributed to the Education State activities and STEM (science, technology, engineering and mathematics) plan via the Tech Schools STEM Future Industries Advisory Panel and the STEM Advisory Committee; represented Victoria on the Forum of Australian Chief Scientists; and participated in a range of advisory committees and funding assessment panels focused on innovation, education and advanced manufacturing.

Leonie has Bachelor and Master of Science degrees from Swinburne University of Technology, and an Executive MBA from the Australian Graduate School of Management. She is also a Fellow of the Australian Academy of Technology and Engineering. In 2014, Leonie received an Honorary Doctorate from Swinburne University of Technology for her contributions to and leadership in scientific enterprises, innovation and the community.

ABMDR
Australian Bone Marrow Donor Registry