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## WHERE TO FIND US

Originally housed in the Falmouth Building at UCT's Faculty of Health Sciences, the SABMR has been at its current location at Groote Schuur Hospital since 2012.

Cover: The main entrance to Groote Schuur Hospital, lit up in the colours of the SABMR in recognition of World Marrow Donor Day.

Photo: Ruvan Boshoff.
INTRODUCTION

The 2017 period saw the South African Bone Marrow Registry (SABMR) coming into its own. Our organisation, which exists to find matched unrelated bone marrow donors for critically ill South African children and adults, has started recruiting its own donors, supported by its partners: the South African National Blood Service, Western Province Blood Transfusion Services and Pathcare.

During 2017 the SABMR made intensive preparations for full accreditation with the World Marrow Donor Association (WMDA), whose audit was conducted in May 2018. We extend our sincere gratitude to Discovery for providing the financial means to enable us to achieve this.

The services we provided to South African patients in 2017 included 45 transplants, eight with an SABMR donor and 37 with an international donor, as well as 236 new preliminary searches and 326 new activated searches. Services to international patients included 221 activated searches, and five transplants with an SABMR donor.

As of 31 December 2017, the donors listed on the Registry numbered 73,027. SABMR Medical Director Dr Charlotte Ingram’s target is to have a South African donor base of 100,000 people. Our challenge is to keep growing the Registry in order to save more lives.

About the South African Bone Marrow Registry

Every year, hundreds of South Africans with blood diseases such as leukaemia reach the point where their only chance of survival is a bone marrow transplant. For about 30% of patients, a matched donor can be found in their own family. For the other 70%, their only hope is to find a matched unrelated donor identified by the SABMR. An internationally recognised registry, this non-profit organisation has over 73,000 donors on its database, and through its participation with Bone Marrow Donors Worldwide has access to over 32 million donors worldwide.

What is bone marrow?

Bone marrow tissue produces red blood cells to carry oxygen, white blood cells to fight infection, and platelets to prevent bleeding. After a transplant, the donor’s bone marrow stem cells travel to cavities in the recipient’s large bones and start producing normal blood.

Why are more donors needed?

The chance of finding a compatible donor is just one in 100,000. Far more local donors are needed because South Africa has a very genetically diverse population and a match is usually found within the same ethnic group as a patient. Every additional donor registered is a potential life-saver for someone in need. To register, see our contact details on the last page of this report.
MESSAGES ...

From the SABMR Chair

Dr Robert Crookes continued to provide leadership as Chairman of the Board of the SABMR during 2017. At the beginning of 2018, he announced his intention to step down from this position and after due process, Mr Derek Auret was elected as his successor. Dr Crookes remains on the Board in his capacity for providing valuable medical expertise and guidance as well as being the chair of the SABMR Medical and Ethics Review Panel (MERP).

‘I appreciate and am humbled by the confidence placed in me,’ said Mr Auret on accepting the position. ‘As the new Chair, while I may not always have the extensive scientific background, nor experience in the field of bone marrow transplantation, I hope to bring other important non-scientific and business leadership skills to the SABMR Board. With the ongoing support of Dr Crookes and the other SABMR Board members and their expertise in the respective areas of medical, transplant, finance and legal aspects, I am confident we can take the organisation forward to fulfil its mission and obligations. In particular I look forward to a new era for the SABMR as we take control and custodianship more actively of our donors, the lifeblood and strength of the organisation. Without our donors we cannot fulfil our mission to serve our patients and bring hope to those in need of transplant. To our donors: “You are our tomorrow”. We salute and thank you for being there and for your selfless contribution and willingness to be part of the SABMR in providing a much needed service to our patients.’

From the Medical Director & CEO

The period 2017 saw my first full year with the South African Bone Marrow Registry (SABMR) as CEO and Medical Director.

Our key priority remains in line with providing a high-quality, safe product and bone marrow stem cell service for South Africa and other registries worldwide, and, as such, the SABMR benchmarks at an international level.

I would like to thank both the SABMR Board and staff for their support and guidance.

The latter part of 2017 saw many changes which necessitated adapting the organisation’s strategy to continue to deliver on the main goal: ensuring more unrelated donors are available for patients in need of transplantation.

Recognising that the strength of the SABMR lies in the support services we provide, being able to make donors more easily accessible, and at the same time complying with international standards, we remain confident that our new strategy of recruiting our own donors with the help of the community and other stakeholders will allow us to deliver on doctors’ and patients’ needs.

I would also like to acknowledge the continued support of our key stakeholders, leaders in government (particularly the Departments of Health and Customs & Immigration for assisting in the logistics of stem cell transport) and other professional associates for their support and ongoing commitment. Finally, I would like to thank our donors for their loyalty and commitment. Their contribution is not only in donating stem cells but saving a life.

Dr Charlotte Ingram
GOVERNANCE, FINANCE and SUSTAINABILITY

Extract of SABMR AFS as at 31 March 2017

SABMR GOVERNANCE

SABMR Board members as at 31 December 2017

Dr R. Crookes (Chairman)
Dr C. Ingram (CEO and Medical Director)
Mrs T. Schiapoff (Deputy Director)
Mr D. Auret
Mr D. Cohen
Mrs J. Hariram
Mrs C. Kotzenberg
Dr S.D. Moodley
Professor N. Novitzky
Dr J. Thomson
Dr M. Vaithilingum

Changes since 31 December 2017

Mr Derek Auret was elected as Chairman. Dr Robert Crookes stepped down as Chairman, but remains on the Board. Dr Jackie Thomson and Mrs Kotzenberg resigned.

Financials provided by H. Tarley & Co
Fundraising has become more important than ever to the running of the SABMR. In 2017, after it became apparent that The Sunflower Fund would no longer be recruiting donors for the SABMR, we entered the era of conducting our own donor recruitment and raising the funds to achieve this.

Baby Marrow & 'Black Tie Maar Ons Gaan Braai'

SABMR Peripheral Blood Stem Cell Donor Quintin Reinecke organised a highly successful fundraiser at the Kempton Park Civic Centre in November 2017, with proceeds split between the SABMR and Child Welfare Kempton Park. The formal, black-tie event 'infused with the friendliness and warmth of a good, old-fashioned South African braai', as he put it, featured a special guest performance by musician Chris Chameleon.

Inspired by Mahatma Gandhi's words 'Be the change you want to see in the world,' Quintin set up a charity organisation called Baby Marrow to help institutions and causes continue their 'selfless service of helping those who need it the most'. We were thrilled to receive over R60,000 from the event.
777MAD: Marathoning a Difference

In 2017 we were approached by Sam Appalsamy, a Wealth and Risk Specialist at Standard Bank Financial Consultancy in Durban. He detailed his awe-inspiring plan to run seven marathons on seven continents to support seven or more organisations ‘doing extraordinary things’, including the SABMR.

Sam's eldest son, Nicholas, was diagnosed with leukaemia at age two, yet has gone on to make a success of his life. Sam himself was involved in two serious motor vehicle accidents, yet has since completed five Two Oceans Marathons and five Comrades Marathons, and has summited Mount Kilimanjaro.

Based on the concept of a marathon being 42 km, he has requested that each supporter contribute R42 to The 777M.A.D. Charitable Trust. The capital amount will be invested to sustain the beneficiaries in perpetuity.

This initiative started on 6 May 2018, with the first race in Vancouver, Canada, followed by races in Brazil in June, Sydney in September and Greece in November. He then runs the Great Wall of China Marathon in May 2019, followed by the Cape Town Marathon, and finally a race in Antarctica in November 2019.

Sam's team includes Dr Kevin Subban, sports doctor to the SA Paralympic and Olympic teams, who is overseeing his training programme, and Dr Glen Hagemann, sports consulting doctor to the Sharks rugby team.

Follow Sam’s progress with the Grand Slam Challenge at
www.777madfoundation.co.za
Instagram:
www.instagram.com/777_M.A.D/
or FACEBOOK:
www.facebook.com/triple7M.A.D/

To become a supporter of The 777M.A.D Foundation and Sam’s efforts to raise funds for 7 or more Foundations, you can donate R42 per race or R294 via the following banking details:

The banking details also appear on the website under ‘Donate Now’.

Walking for Life

In 2017, media producer Darren Combrink from Digital Shelf, which handles our branding and social media, decided to walk the Camino de Santiago pilgrim route in Spain to raise funds for the SABMR. Between June and July 2018, he will cover 825 kilometres armed with a GoPro and social media. 'We can save children who are dying right now,' he wrote on his campaign page. 'Out of 79 children referred to SABMR in 2017, only 19 had adequate funds for a donor search.'

For more information see
www.backabuddy.co.za/walkingforlife
A FRESH NEW LOOK

You may have noticed a change in the look and feel of our branding.

To reflect the new SABMR, in 2017 we engaged a new media partner, Digital Shelf in Cape Town, to freshen up our look and help us engage with more potential donors and supporters via various channels including social media.

We also commissioned talented illustrator Monique Mouissie to produce new cartoons for the SABMR website. Her designs, which accompany eight revised steps on the donor process and patient journey, will help us reach out more effectively to patients, and quickly and clearly communicate what is required from donors.
COMPLETING THE CIRCLE

We have been working more closely with our partners in the past year in order to secure our circle of support.

2018 will see our partners, the South African National Blood Service, Western Province Blood Transfusion Service and Pathcare, assisting the SABMR with a new donor recruitment model in which we enrol our own bone marrow donors. The Laboratory for Tissue Immunology (LTI), a key partner to the SABMR, has been testing donors for some time. The LTI, which is accredited by the European Federation for Immunogenetics, provides an international standard of HLA typing for donor-recipient matching.

SABMR OUTREACH

In 2017 a concerted effort was made to build stronger relationships with our partners. The SABMR went on a roadshow, visiting transplant centres in Gauteng (Alberts Cellular Therapy at Netcare Pretoria East Hospital; Mary Potter Oncology Centre at Life Groenkloof Hospital, Pretoria; Charlotte Maxeke Johannesburg Academic Hospital) and Cape Town (UCT Private Academic Hospital and Groote Schuur Hospital, and Haemalife Practice at Netcare Kuilsriver Hospital). Our aims were firstly to educate staff on what we do, and secondly to hold feedback sessions to fill in any gaps in our service, asking the question, 'What do our transplant centres need from us?'.

We have also revised and updated our application and consent form for new recruits, as part of the new model for recruiting donors in-house.
COMMITMENT TO QUALITY

WMDA Accreditation Package Submission
Thanks to a generous grant from Discovery, the SABMR was able to submit its application package for Full Accreditation with the World Marrow Donor Association on 14 December 2017.

Risk Register; Business Continuity, IT & System Back-up Policy and Disaster Recovery Process
The Risk Register was established following input from Mazars to map the overall risk profile of the SABMR as well as to log incidents. The Business Continuity, IT & System Back-up Policy and Disaster Recovery Process document was devised to comprehensively catalogue the key business processes of the SABMR and the necessary procedure to back-up and restore application data.

Standards for a South African Bone Marrow Registry
The SABMR is working with the National Department of Health to formulate the national standards for a registry of unrelated bone marrow stem cell donors.

Appointment of Quality Manager
Also thanks to the Discovery grant, the SABMR was able to employ a Quality Manager. Ingrid McDonnell, who has a background in quality systems in blood products, was appointed to this post during 2017.

EXTERNAL QUALITY ASSESSMENT

The United Kingdom – National External Quality Assessment Service (UK-NEQAS) focusses on programmes to ensure clinical relevant quality is maintained. The SABMR participates in the Educational Scheme, Clinical Scenario component of this international quality assurance system. During 2017, the SABMR participated in two exercises.
PATIENT STORY

'My donor gave me a chance to do the things I want to do in life'

In 2005, four-year-old Zyaan Makda from Mitchell's Plain went on a plane trip and experienced such painful ear popping that her mother took her directly to a doctor at home in Cape Town. 'I'd always been a pale child,' says Zyaan, 'and the doctor thought I had anaemia.' Iron supplements turned toxic in her body, and eventually she was diagnosed with thalassaemia minor, an inherited blood disorder in which the body makes abnormal haemoglobin, the protein in red blood cells that carries oxygen.

For years Zyaan needed regular blood transfusions at Red Cross War Memorial Children's Hospital, eventually fortnightly. As a bone marrow transplant could provide a possible cure, Zyaan was referred to the SABMR. No local donors could be found, however, and the odds of finding the rare match for her internationally were just seven in 30 million. Then the miracle happened.

'Early in 2017, the SABMR called,' says Zyaan. 'Out of nowhere this lady from Germany popped up – a 100% match! I was very happy, and nervous too.'

Thanks to the SABMR's ties with the German registry, Zyaan received her transplant in August 2017 at UCT Private Academic Hospital, overseen by Professor Nicolas Novitsky. Zyaan received bone marrow from her donor, as opposed to peripheral blood stem cells (PBSC), which meant her convalescence would be longer (an average of 28 days) than that of a patient who had received PBSC (seven to 14 days' convalescence). Owing to her condition, she suffered seizures after the transplant and was put in a medically induced coma, then needed emergency surgery. But after 80 days in hospital she went home with her gorgeous smile intact, to the delight of her family.

Now the 16-year-old, an ardent Harry Potter fan, is in Grade 12 and planning to study medicine. 'I'm feeling much better and picking up weight. I'm looking forward to doing normal teenager things – going out with my friends, having sleepovers, not having to worry so much,' Zyaan says. 'My donor gave me a chance to do the things I want to do in life, and I'll be eternally grateful for that.'
DONOR STORY

In 2017 Vishen Govender became one of a select few SABMR donors who agreed to provide bone marrow instead of peripheral blood stem cells.

Vishen Govender, a fifth-year medical student at the Nelson R Mandela School of Medicine, has donated blood regularly since the age of 16. While donating blood in 2016, he was asked during a registration drive whether he was interested in signing up as a bone marrow donor. Vishen's thoughts were, 'If I can give blood, I can be a stem cell donor. There's not much difference'. Registering was a 'shot in the dark' for this 23-year-old, who believes service to humanity is service to God. Selflessness is a central value to his family and Hindu culture. 'Blood donation is sacred to us; it is termed "liquid love",' explains Vishen. The global spiritual organisation Shri Sathya Sai advocates blood donation drives in his local community, part of Seva (selfless deeds of kindness). 'It is through this organisation that I realised the importance of blood donation,' says Vishen. 'My parents have been donating blood for years, and when my brother turned 16 this year he started blood donation too.'

Seven months after his registration as a bone marrow donor, Vishen received a phone call from the SABMR: he was potentially a match for a very ill child overseas. 'I was a bit shocked at first – I didn’t think I would be a match for anyone! But I thought, “I’m up for this. If I can grant the gift of life and make a difference, why not?” It's how I was raised.' He discussed it with his parents and best friend, who were very supportive. Then came the lengthy process, involving numerous blood tests, to discern whether he was indeed a perfect match for the patient. Finally, during a semester vacation from his studies at medical school, Vishen was flown to Johannesburg for the procedure at Netcare Pretoria East Hospital.

Vishen's donation was unusual in that he did not donate peripheral blood stem cells via intravenous line, as is the norm in South Africa, but donated actual bone marrow. Under very particular conditions, an SABMR donor may be approached to donate bone marrow instead of peripheral blood stem cells. In this case, the reason was the age of the recipient. Bone marrow is better for children as it has more immature cells and ensures better engraftment than peripheral blood stem cells. Vishen spent a day in hospital, including two hours in theatre where needles were inserted into his pelvic bones to extract the bone marrow.

Vishen Govender with his parents
'Everything went well and I was taken good care of,' he reports. 'A little bit of pain to save someone's life is not too bad! For a few days of discomfort, someone will have a lifetime of joy. It's worth every effort.'

Since the donation, Vishen has been an advocate for bone marrow donation in his community. 'Family and friends wanted to know more, so I've encouraged a lot of people to sign up. I'd like to raise awareness at university too,' he says.

He describes how his view on life has shifted since the event. 'It was a life-changing experience which restored my faith in humanity, and emphasised the importance of the power of humanity. You never know who will be your saviour. We live in a global village in which help can be called upon from anywhere in the world.'

DONOR-RECIPIENT MEETING

Four years after his life-saving bone marrow transplant, Capetonian Richard Jupin, 55, met his donor, Megan Erasmus.

It's been a long journey to health for Richard Jupin. A senior instructor in the radiation protection field at Koeberg nuclear power station, Richard was diagnosed with chronic lymphatic leukaemia at age 30. He underwent regular chemotherapy for 19 years – until it simply 'stopped working'. His physician, Dr Kevin Gartrell, recommended a bone marrow transplant as the only viable solution. Within a few months, the SABMR had found a perfect 10/10 tissue match in Megan Erasmus from Empangeni. 'When they told me, it was glorious!' says Richard.

His wife Hayley and their teenaged children Courtney and Matthew attended his transplant at Constantiaberg Mediclinic in June 2013, performed by Dr Mike du Toit. Richard later needed an emergency top-up of Megan's lymphocytes (infection-fighting white blood cells), so Megan flew to Cape Town to donate for a second time. 'That did the trick. Afterwards I started to come right,' says Richard.

Now on no medication whatsoever, he enjoys his work, his family and his hobbies – photography and keeping koi fish. Full of gratitude, he says, 'My peak fear was always that I wouldn't see my kids grow older.' Thanks to Megan, he is there for his 'lovely wife and children', and has seen both Courtney and Matthew matriculate and start their studies. 'I would also like to profusely thank the staff at the SABMR and the bone marrow unit at Constantiaberg Mediclinic for their endless dedication to their work,' he says.

As both Richard and Megan were keen to meet, the SABMR arranged the event in November 2017. Megan, 32, a public relations officer for Kloppers Inc Attorneys

'My peak fear was always that I wouldn't see my kids grow older'
in Empangeni and Richards Bay, had been contacted unexpectedly by the SABMR six years ago to inform her that she was a potential match for a patient. She had joined the Registry some years previously during a family crisis she only vaguely remembered. A member of her extended family had been diagnosed with leukaemia, and the family had been tested in an attempt to find a bone marrow match for him. Sadly, no match was found and he died shortly afterwards.

Was she willing to donate her stem cells? 'There was absolutely no doubt in my mind that I would do it,' says Megan. 'I would ask the same of another human being.' She donated at UCT Private Academic Hospital in Cape Town. All she knew of her recipient was that he was a middle-aged South African man.

On the meeting day at the SABMR offices, Richard and Hayley met the SABMR team and were taken into the boardroom, where a tea had been laid out and Megan and her fiancé Clinton were waiting. 'It was truly something else,' says Richard. 'I'd armed my pockets with tissues! We had good hugs, good chats. What do you give or say to someone who has saved your life? Megan literally did that. If she hadn't been registered as a donor, or hadn't been available to donate, I'd be under the ground right now. I just profusely thanked her.'

Megan says, 'When Richard walked in, wow. It was quite an emotional moment. At one point Hayley thanked me for the top-up. If Richard hadn't had that, she said, he wouldn't have survived. It was an eye-opening moment: if I'd not been available that week, if I'd been doing something frivolous which I considered important, he might not have made it. It dawns on you.'

They spoke at length, after which they were taken to The Wild Fig in Observatory for lunch, where Dr Mike du Toit – the 'wizard doctor' who performed Richard's life-saving transplant – joined them. In the afternoon, Megan and Clinton flew home. 'The worst thing was saying good-bye,' says Richard. 'I still want to give her another hug! What an absolutely amazing young woman. I was truly honoured to meet her and be in her presence.'

Richard and Megan stay in touch and have become friends on Facebook, where they posted photographs from their meeting.

Says Megan, 'The response from Richard's friends on Facebook was so overwhelming. He is a loved person. He's had all this life experience, he cares about the environment, he's a contributing member of society. If he'd been lost, it would have been a tragedy.'
GLOBAL COLLABORATION

The SABMR is a member of international working groups including GRID (Global Registration Identifier for Donors) and Prometheus, the internationally used information system for stem cell donor registries.

The World Marrow Donor Association (WMDA)

On behalf of its members, the World Marrow Donor Association (WMDA) promotes global collaboration and the sharing of best practices for the benefit of stem cell donors and transplant patients.

WMDA was informally initiated in 1988 by three pioneers in the field of transplantation: John Goldman (United Kingdom), E. Donnell Thomas (United States) and Jon J. van Rood (the Netherlands). This led to the foundation of WMDA in 1994. In 2007, WMDA became one of the founding members of the Worldwide Network for Blood and Marrow Transplantation.

In 2017, WMDA took over the activities of the NetCord Foundation. In addition, it incorporated the global donor registry resource, Bone Marrow Donors Worldwide (BMDW), now known as the Search & Match Service of WMDA. This database includes the unique HLA information of over 32 million volunteer stem cell donors and cord blood units worldwide. In this database, physicians and search coordinators can search for a matched donor for their patients in need of a stem cell transplant.

WMDA is led by the WMDA Board and committees, whose members are all experts in their fields. Day-to-day activities are carried out by the WMDA office, a team of professionals based in Leiden, the Netherlands.

In pursuing its mission, WMDA acts exclusively in the interest of donors voluntarily donating their haematopoietic stem cells to patients in need of a transplant. WMDA is bound by core values of independence, integrity and transparency.

The activities of WMDA are based on four pillars:

- **Optimising Search, Match & Connection:** Provide a global platform that facilitates access to the most suitable stem cell source for a transplant patient;
- **Supporting global development:** Support members to develop and grow, so that more transplant patients find the most suitable match;
- **Promoting donor care:** Assure that the rights and safety of stem cell donors are promoted and protected;
- **Ensuring quality:** Promote product quality and global collaboration through accreditation and standardisation.
To mark World Marrow Donor Day on 16 September 2017, we featured the story of bone-marrow recipient Zanelle Britz (pictured), who plays the double bass in the Cape Town Philharmonic Orchestra, on our Facebook page.

We also uploaded a moving video of a donor-recipient meeting onto the SABMR website for public viewing.

An-Louise Joubert met her anonymous stem cell donor, Chris Schutte, in September 2016. Chris was the match who enabled her to survive after being diagnosed with severe aplastic anaemia at the beginning of her first year at Stellenbosch University. At their warm and emotional meeting, An-Louise and her family expressed their heartfelt gratitude to Chris for his act of humanity.

Today An-Louise, 27, is on no medication whatsoever. ‘I have a normal, happy life. There’s nothing holding me back,’ she says. She lives in De Doorns with her husband Dirk, a hotel general manager, and after working in wine marketing, is enjoying a new career as a wedding coordinator.

She encourages South Africans to register as bone marrow donors. ‘Imagine if it happened to you. There’s someone like you, lying in a hospital bed wishing they could be active and go outside. You can save that person’s life.’
MEETINGS ATTENDED
International Meetings

WMDA Spring Meeting,
Marseilles, France, 24 - 25 March 2017

Three of our staff members attended the World Marrow Donor Association (WMDA) Spring Meeting: Dr Charlotte Ingram, Medical Director and CEO, Deputy Director Terry Schlaphoff, and Veronica Borrill, Donor Liaison and Harvest Coordinator.

Representatives from 35 countries were in attendance to give input to set new strategies to take WMDA forward after its amalgamation with Netcord and BMDW (Bone Marrow Donors Worldwide) in January 2017.

This was a very busy meeting, with two days of early starts and a packed programme of lectures, workshops and working group meetings. Among the sessions attended were the following:

- Search Coordinator Course 2015 -2017 and the Future: Apart from existing courses, WMDA will add a third level. The intention is to create a community among search coordinators and a platform for discussion topics. Courses will be run twice a year. Advanced Level this year had 42 students, including two from South Africa.

- Emerging Registry Program: WMDA has started a handbook to assist emerging registries. A brainstorming meeting was held, in which Brazil, Lithuania and South Africa were invited to participate to define what more could be done.

- During EU Directives Regarding Single European Coding (SEC 4) and Imports, Dr Alexandros Spyridonidis from the Greek registry, Centre of Bone Marrow Donor Volunteers – Save a life, gave a brief overview of the Coding Legislation with reference the Single European Code (SEC).

- We attended the GRID (Global Registration Identifier for Donors) & SEC (Single European Code) Implementation session, and the GEMS Meeting (Group of European Medium-Sized Registries). As associate members of the GEMS group, we may participate in its activities.

We would like to thank the Board for supporting our visit to this meeting. With spring comes new growth, and this meeting yielded an abundance of ideas around strategy and future planning at a time when we were doing exactly that at the SABMR. Ideas from the meeting were shared at our Strategy Planning Meeting on 26 April 2017.
WMDA Fall and NMDP Council Meeting, Minneapolis, USA

Dr Ingram and Jane Ward, Harvest Coordinator, attended the WMDA Fall and NMDP Council Meeting in November 2017.

WMDA Fall Meeting,
8 – 9 November

The first two days involved the various WMDA working groups, a great opportunity to interact with colleagues from all over the world, with whom we normally only communicate via email, telephone or Skype.

During one of the sessions, Alana James, CEO of The Sunflower Fund, announced the launch of the Stem Cell Registry Alliance together with the Nigerian Bone Marrow Registry, Caribbean Bone Marrow Registry, African Caribbean Leukaemia Trust, Danny Whyte and Ivor Burford Leukaemia Trust and the Kevin Kararwa Leukaemia Trust.

NMDP Council Meeting,
10 – 11 November

Donor centres and registries from around the world attend this very informative, very busy meeting every year. Days are filled from morning to evening with one- to two-hour sessions. This year these included 'HLA Search Strategy', 'Optimizing Collections using a Prediction Algorithm', 'Queen of Hearts and Jack of Backs: Assessing Cardiac and Back Issues', 'Ethical Dilemmas in Haematopoietic Cell Transplantation', 'The Diverse World of Bugs Within: How the Microbiome Affects Transplantation', and many more.
Local Meetings

South African National Blood Transfusion Congress,
Sun City, 28 - 31 August

We attended the congress, subtitled 'Innovation – Lifeline to the Future', at Sun City Resort in the North West Province. The aim of the congress was to present a forum for showcasing achievements, solving problems, sharing knowledge, and generally broadening the knowledge base of blood transfusion in South Africa and internationally.

Present at the congress were staff from the South African National Blood Service (SANBS), Western Province Blood Transfusion Service (WPBTS) as well as international blood transfusion centres, Namibia and Nigeria to name a few. Dr Charlotte Ingram, Alicia Venter and Jane Ward represented the SABMR.

Alicia Venter, Search Coordinator, and Jane Ward, Harvest Coordinator, both presented at the congress, ‘The effect of ABO matching on overall survival following hematopoietic stem cell transplantation from a matched unrelated donor’ and ‘HLA-B*15 Diversity in the South African Bone Marrow Registry' respectively.

The 14th South African Stem Cell Transplantation Society (SASCeTS) Conference,
Sandton, 10 - 11 November 2017

The SABMR presented two papers at the meeting, held at the Protea Hotel Balalaika in Sandton. The presentation by Dr R. Crookes on the SABMR standards was aimed at fulfilling the request by the National Department of Health that the document receive external review. Via SASCeTS this document would be circulated to Transplant Centres and other stakeholders.

A key issue raised at the SASCeTS AGM was the change in the relationship between SABMR and The Sunflower Fund (TSF), and the plans for TSF to change their operating model to no longer recruit donors for the SABMR.
The 2017 SATiBA conference and AGM was held at Leriba Hotel & Spa, Centurion. The two-day programme was filled to the brim with speakers from all walks of life, sharing their cultural experiences, research findings and professional expertise. Among them was Mqondisi Tshabalala from the Institute for Cellular and Molecular Medicine at the University of Pretoria, who presented a paper co-authored by Dr Charlotte Ingram, Terry Schlaphoff and Veronica Borrill on allele and haplotype frequencies from donors on the SABMR.

Adjacent to the conference hall, an exhibition area was set up providing a space to network amongst peers and pick the brains of exhibitors such as National Speed Blood Services, SANBS, Next Biosciences and the SABMR. To create awareness and interest amongst attendees, the SABMR had a small stand with patient information, information on becoming a donor, and a heart-warming video of a recent meeting between a transplant patient and her stem cell donor.

The SABMR table at the SATiBA Conference

SATiBA is a not-for-profit organization that aims to support all South African tissue banks
SOURCES OF DONORS for South African Patients

To date, the SABMR has facilitated collections, from both unrelated and family donors, for international patients in these countries:

Australia 1
France 1
Germany 3
India 1
Portugal 1
Spain 1
Sweden 1
The Netherlands 2
United Kingdom 3
USA 10
ASSISTING BONE MARROW REGISTRY NIGERIA

In 2017 the SABMR was honoured to assist Bone Marrow Registry Nigeria (BMRN) in facilitating the harvest of stem cells for a critically ill patient overseas. BMRN was established in 2012 by Seun Adebiyi and has 839 registered donors. With the odds of finding a match at just one in 100,000, it was all the more astonishing that a match was found among its relatively small database of donors.

Donor C.U.* is a young medical doctor currently finishing his housemanship in Nigeria. As a regular blood donor for many years, it was a natural progression for him to sign up for bone marrow donation. ‘It was our professor at medical school who introduced us to stem cell donation at a Saturday morning lecture,’ he says. The professor gave an introduction to blood transfusion, ‘then told us the story of the Nigerian Registry founder, Seun Adebiyi, about why they were opening a registry in Nigeria, and the need for us to register as donors. So after the lecture we had our cheek swabs done and then registered.’

Three years later, C.U. was contacted: he had been identified as a possible match for an anonymous patient overseas. A series of blood tests confirmed that he was indeed a perfect match, and, in the absence of collection facilities in Nigeria, he agreed to fly to South Africa for the stem cell donation, organised by the SABMR. About his feelings en route to Cape Town he says, ‘I just felt like I was going to save a life, so I was hoping within me that the patient would survive after all the efforts.’

C.U., accompanied by his brother, stayed in Cape Town for almost two weeks. Preparing for stem-cell collection entails five days of injections of Neupogen, a man-made form of a naturally occurring growth hormone, to stimulate the large bones to produce extra stem cells. The donation took place at a Cape Town hospital. ‘There were no difficulties encountered, and the SABMR donor welfare officer, Hazel, was there to cheer for me all through it, as well as nurse Roxanne. They did a great job, and the doctors were reassuring too,’ says C.U.

C.U. and his brother enjoyed some sightseeing, visiting the V&A Waterfront and Table Mountain, before returning home. He says, ‘I admire the level of commitment shown by the SABMR during my stay, Jane, the Harvest Coordinator, was always calling the hotel to talk with me since I couldn’t get a South African SIM card.’

He was grateful the donation had been a success and that his stem cells went overseas immediately for the patient’s transplant. ‘I felt so much relief afterwards. Overall, it’s a nice experience seeing such trans-national cooperation to save a life.’

* International rules governing the anonymity of donors and patients stipulate that a donor and patient cannot be identified fully for the first few years after a donation. After this time period, disclosure is subject to the approval of both parties’ registries and physicians.
Meet our new staff

**Siphokazi Dyasi** joined our staff as a data capturer and admin assistant in July 2017, after working as an arbitrations intern for the Building Industry Bargaining Council. ‘I’d graduated and was looking for a job when I got a call from an agent, saying the client wanted to meet me. I had no clue of what the SABMR was!’ But before the interview she had a chance to read the book on the SABMR, *An Uncommon Gift*, which gave her insight into our work. ‘Knowing that I’m not just capturing forms but potential life-savers - that’s what makes me not take my job for granted,’ she says.

**Ingrid McDonnell** began work as Quality Accreditation Officer in July 2017. Previously, she worked for the Western Province Blood Transfusion Services as the QA Supervisor, and for the Africa Society for Blood Transfusion as the Documentation Assistant. Says Ingrid, ‘I really enjoy working with the staff at SABMR – there is a real sense of family here. I like the fact that our work is of huge importance to so many lives out there.’

**Lisa Merryweather** started work as a search assistant at the SABMR in August 2017. Prior to this, she worked as a microbiology medical technician. A wish to contribute led to the change. ‘I want to make a difference; I want to help others however I can,’ she says. Something she values about the new position is the contact with bone marrow donors. ‘I enjoy the conversations I have with our donors. They’re so friendly, eager and willing to help in any way they can.’

End-of-year function

SABMR staff enjoyed their 2017 end-of-year function at the Cape Town Fish Market at the V&A Waterfront. Our theme alluded to purple, inspired by Jenny Joseph’s poem *Warning* (*When I Am An Old Woman I Shall Wear Purple*).
Volunteering with passion:
Yvonne Lewin

Volunteer worker Yvonne Lewin, who celebrated her eightieth birthday in January 2017, is proud to be helping save lives at the SABMR. Yvonne assists the team in loading details of new donors onto the SABMR database and retrieving data from the archives to update information of existing donors. She has also acted as a stem cell courier for the SABMR, transporting a precious bag of stem cells for a patient about to undergo a bone marrow transplant.

After retiring from her successful career as a travel agent in 2000, Yvonne was approached by a former client, Professor Ernette du Toit, previous Medical Director of the SABMR, about possibly doing voluntary work. 'I'm not someone who is able to sit idly, so when Prof du Toit mentioned that the SABMR could use a spare pair of hands, I jumped at the opportunity,' she says.

'We are truly grateful for all the time that Yvonne has generously dedicated to our worthy cause,' says Dr Charlotte Ingram, Medical Director. A special tea was held at the SABMR's offices to celebrate Yvonne's milestone birthday and to acknowledge her contribution to the organisation. Thank you, Yvonne!

You’re never too old to give back

Veronica Borrill, Dr Charlotte Ingram, Terry Schlaphoff, Yvonne Lewin and Professor Ernette du Toit

“Ageing is not lost youth, but a new stage of opportunity and strength.” — Betty Frieden

One such lady who has embraced this new stage is Vredehoek resident, Yvonne Lewin. Following her recent 80th birthday, she still devotes her energy to helping save the lives of others through her volunteer work at the South African Bone Marrow Registry (SABMR).

In July 2000, just four days after retiring from her successful career as a travel agent, Yvonne (who was then 63 years old) was approached by her former client and founder of SABMR, Professor Ernette du Toit, to assist the Registry on a voluntary basis.

Comments Yvonne: “I am not someone who is able to sit idly, so when Prof. du Toit mentioned that the SABMR could use a spare pair of hands, I jumped at the opportunity.”

Today, 80-year-old Yvonne assists the team in loading details of new donors onto the SABMR database and retrieving data from the archives to update information of existing donors. In earlier times, Yvonne also acted as a stem cell courier for the SABMR.

The SABMR recently held a special tea at their offices in Observatory to celebrate Yvonne's birthday and pay tribute to her efforts in assisting the organisation.

Comments Dr Charlotte Ingram, Medical Director of the SABMR: “We are truly grateful for all the time that Yvonne has generously dedicated towards our worthy cause and are delighted to join her in celebrating her 80th birthday.”
The SABMR is moving ahead in improving the tissue-typing quality of its donors, recruiting its own donors, and raising funds to support these activities.

Made possible by the more sensitive technology now available, better-typed donors on the database will shorten the time it takes to find a match for someone in need of a bone marrow transplant. ‘We will be working on increasing both the quality (better typing) and quantity of donors on the Registry to find the life-saving match faster,’ says Dr Charlotte Ingram.

The SABMR encourages potential donors to sign up with us directly.

Our DIY Buccal Swab Kit

The SABMR moves to do-it-yourself sampling for prospective donors. Seen here is our Buccal Swab Kit.

Filling in the Consent Form

Using a swab to collect a sample
How You Can Help

Register as a bone marrow donor.
Any person between the age of 18 and 45 who meets our eligibility criteria may register as a donor. To join the Registry, please go to www.sabmr.co.za, call 021 447 8638 or email donors@sabmr.co.za.

Donate funds to the SABMR.
As a non-profit organisation, we rely on donations to continue our life-saving work. See www.sabmr.co.za and make a financial contribution by clicking the 'Donate' button.

Contact the SABMR:
PO Box 13353
Mowbray 7705
Cape Town

Phone: 021 447 8638
Email: admin@sabmr.co.za
www.sabmr.co.za

Our Stories
Shared

An Uncommon Gift: The Story of the South African Bone Marrow Registry and the lives saved by stem cell donation was published to mark the SABMR’s 25th birthday in 2016.

This beautifully produced book details the founding and achievements of the SABMR, and includes the stories of some patients and donors as well as a selection of heart-warming anonymous letters exchanged between donors and recipients.

Available for sale (R200) at www.sabmr.co.za.
You could be someone’s TOMORROW!

Are you between the ages of 18 and 45? No pre-existing health conditions? **REGISTER TODAY** to become an SABMR stem cell donor.

www.sabmr.co.za