

Submission to the Australian bone marrow transplant sector review

Improving ethnic diversity on the Australian & worldwide stem cell registries



Education

Awareness

More lifesaving matches

Contents

Introduction..... 3

About UR the Cure..... 4

Executive summary..... 5

Recommendation 1..... 6

Recommendation 2..... 8

Recommendation 3..... 10

Recommendation 4..... 13

Recommendation 5..... 16

Recommendation 6..... 18

Conclusion..... 19

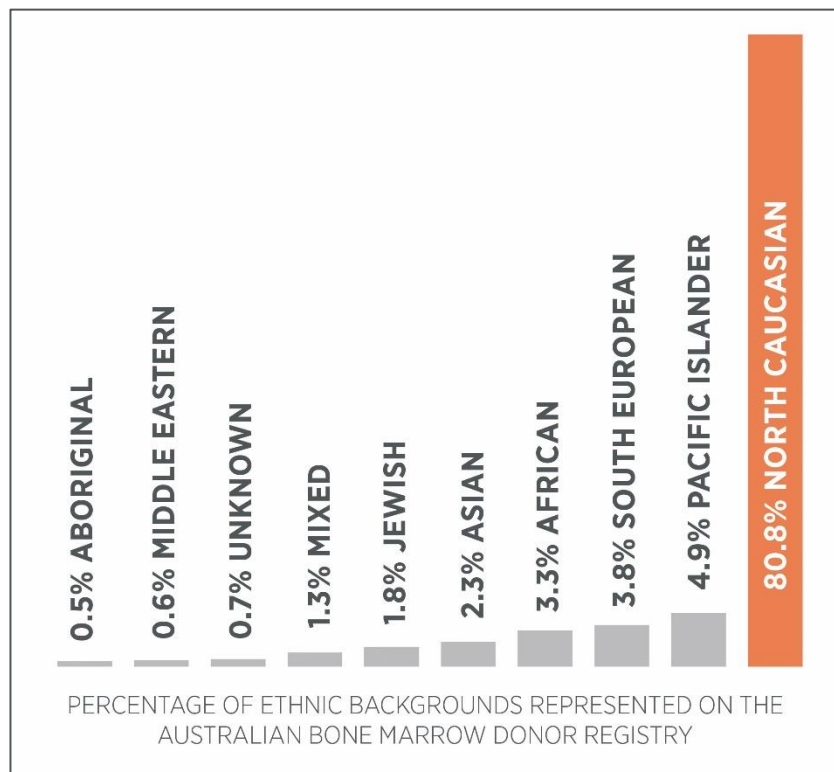
References..... 20

Appendix..... 22

Introduction

Thank you for the opportunity to contribute to the review of the Australian bone marrow transplant sector. The work done by the Australian Bone Marrow Donor Registry (ABMDR) over the past 25 years is to be applauded, however the ongoing lack of ethnic and indigenous diversity on the Australian Bone Marrow Donor Registry, the underlying causes for this lack of diversity and the impact it has on the equality of health outcomes must be better understood and addressed as a matter of urgency.

“To be told that my last chance for a cure was a stem cell transplant after years of hard treatment was devastating. What was even more devastating was to hear that I may not have that lifesaving transplant because of my ethnicity. UR the Cure is advocating for change that we desperately need in Australia because everyone, no matter what their ethnic background should have the same chance for a cure” – Pamela Bousejean, Founder of UR the Cure





About UR the Cure

UR the Cure was founded by Pamela Bousejean after her personal struggle to find a stem cell match due to her ethnicity. UR the Cure is a Registered Charity under the Australian Charities and Not-For-Profits Commission Act 2012, its goal is to increase the number and diversity of donors on the ABMDR through awareness campaigns and targeted education programs.

In developing this submission, UR the Cure has worked collaboratively with patients and family and friends of patients who have been, or are currently impacted by the lack of ethnic diversity on the Australian and global bone marrow donor registries. Input has been provided by the “Find Tan a Donor” campaign and discussions have been undertaken over the years with key services in Australia including hospitals and not-for-profit organisations and overseas donor recruitment organisations.

This submission aims to advocate on behalf of all those affected by the lack of ethnic diversity on the ABMDR with over 500 people providing input and support for the recommendations through a survey developed by UR the Cure; “Australian bone marrow donor recruitment strategies survey,” conducted between April 2017 and May 2017.

Executive Summary

UR Cure is making 6 key recommendations that we believe will support the ABMDR to achieve an appropriately diverse bone marrow donor registry.

Key Recommendations

1. Establish a structure focused on and responsible for diverse donor recruitment which has the ability to fundraise
2. Implement cheek swab HLA (Human Leukocyte Antigen) testing as a matter of urgency
3. Maximise opportunities to recruit ethnically diverse bone marrow donors through blood donors at the Red Cross Blood Service
4. Support and maximise patient drives as opportunities to drive diversification of the ABMDR
5. Design and implement awareness and education programs targeted at ethnic and indigenous communities to proactively promote people joining the ABMDR
6. Improve transparency and accountability of ABMDR diversification and performance

Recommendation 1 - Establish a structure focused on and responsible for diverse donor recruitment which has the ability to fundraise

Rationale

There is currently no agency or group in Australia specifically responsible for driving donor recruitment to represent Australia's multicultural population. The governance model between the Australian Red Cross Blood Service and the Australian Bone Marrow Donor Registry (ABMDR) is complex and there is no team within either organisation whose mandate and skill set is solely focused on actively driving and supporting donor recruitment, awareness and education campaigns.

There is no fundraising capability to help achieve the goals of increasing the number and diversity of donors on the ABMDR. This is in comparison to overseas organizations such as 'Be The Match' (USA), 'DKMS' (primarily Germany and UK), Anthony Nolan (UK) and Stem Cell Club (Canada) which are innovative, flexible and responsive. The 'Gift of Life' in America were the first registry in the world to utilize cotton swab q-tips to test donors and implement online donor recruitment and were able to be this innovative due to their privately funded model. Although we understand more research needs to be done to determine the pros and cons of different funding models and that a completely privately funded model may not be the best fit for Australia's landscape, we do believe that Australia's current model is too restrictive and must be reviewed and changed in order to achieve the goals.

The absence of a representative organization in Australia

In a recent media report on Channel 10's "The Project", UR the Cure was the only organisation who provided the necessary information to the journalists and made comment on the topic as well as being the only organization answering the influx of questions that appeared on the Facebook page on the report afterwards. UR the Cure is run solely by Pamela Bousejean (an ex-patient) and it is run purely based on a passion and an attempt to fill the large gap that exists in Australia.

Specific Recommendations

- 1.1 A structure is established with a mandate to drive ethnically diverse donor recruitment.
- 1.2 The revised structure is well-funded.
- 1.3 The revised structure allows for the ability to fundraise.
- 1.4 The revised structure is accountable for understanding and incorporating best practice recruitment models, innovation and evidence based practice.
- 1.5 Consumer engagement and representation informs donor recruitment design and strategies.

82% of survey respondents believed that a structure that allows for more funding is necessary to improve donor recruitment strategies in Australia

Recommendation 2: Implement cheek swab HLA (Human Leukocyte Antigen) testing as a matter of urgency

Rationale

Cheek swab testing simplifies the donor registration process and would improve ease of access and acceptance into under-represented communities and younger populations. It allows for broad and rapid engagement.

Although there are perceived challenges of a higher “drop out” rate (ie- the notion that people recruited through cheek swabs are more likely to withdraw when matched), this can be overcome through careful registration processes that ensure good education and informed consent at the time of recruitment. To overcome the perceived challenge of a higher dropout rate, guidelines including the World Marrow Donor Association (WMDA) informed consent guidelines, which are currently being practiced by international organisations can be utilised.

Conference Poster from Canada’s “Stem Cell Club”

Two studies by Switzer et al. found that donors who felt less informed at various points in the donor recruitment, evaluation, and workup process were more ambivalent about donation and less likely to proceed with the donation process if asked. Our group’s strategy for securing informed consent at drives aims to lessen the ambivalence of the donors we recruit, and can be easily adopted by any registry, individuals or groups that organize stem cell drives.

When people are well informed and understand what’s involved when donating stem cells and how easy it can save a life, it is our experience that people are more than willing to join the ABMDR, even those with fears, such as fear of needles.

“I don’t like needles but hell, if someone said to me we need to stick some needles in you because you could save someone’s life then I would do it in a heartbeat” – Friend of a patient searching for their match

Cheek swab testing has been adopted for many years by overseas organisations including the UK, USA and Canada and has been integral to finding donors for many ethnically diverse patients, such as those developed by the ‘Stem Cell Club’. This group has been able to successfully recruit over 6000 people through the use of cheek swabs since November 2011 (as of December 2016).

“Here in the United States, we sign up potential donors through cheek swab/saliva sample testing. As a result we can hold drives regularly throughout the United States, just about anywhere, including at events where the majority of attendees are Indian or South Asian (the ethnic group who is most likely to match my brother).”

– Brother of an Australian patient

Cheek swab testing is something the Australian public has supported in the past. Over 500 people in 2016 signed a petition, “Introduce cheek swab testing to increase bone marrow/stem cell donors in Australia”.

Specific Recommendations

- 2.2 The ABMDR adopt cheek swab registration processes as a matter of urgency.
- 2.3 If the roll out of cheek swab testing is anticipated to take longer than 6 months, the ABMDR considers adopting a staged roll out to immediately support drives that are targeting priority populations (young and ethnically diverse).
- 2.4 Utilise online ordering systems to quickly and effectively distribute cheek swab kits.

88% of respondents believed that cheek swab testing needs to be implemented to increase the numbers and diversity of donors on the ABMDR

Recommendation 3: Maximise opportunities to recruit ethnically diverse bone marrow donors through blood donors at the Red Cross Blood Service

Rationale

Although we highly recommend cheek swab recruitment to be implemented as a matter of urgency, we believe that the blood service can complement the cheek swab registration process and should play an important role in increasing the numbers and diversity of the ABMDR's donor pool.

The blood service and its structure has an existing system that allows for blood samples to be taken and registered with the ABMDR. The blood service is another avenue to recruit bone marrow donors and can better maximize opportunities if small operational changes are made.

Currently the Red Cross Blood Service has no mechanisms to identify blood donors who fit the criteria of the required donors for the ABMDR (young and ethnically diverse). This means many people who are the perfect candidate and who are already donating blood are not given the opportunity or even information about joining the ABMDR.

81% of survey respondents with an ethnic or indigenous heritage and are currently in the correct age range to join the ABMDR were not offered information about the ABMDR at the time of their blood donation

The eligibility criteria to donate blood overrides the eligibility to join the ABMDR resulting in perfect candidates for the ABMDR being rejected and potential lifesaving matches lost. For example many people are rejected from joining the ABMDR because they lived in the UK during the mad cow disease period.

"I was rejected from (joining) the ABMDR as I'm 45 kg and under the weight limit" – Asian survey respondent, Family member of a patient/ex-patient

The above quote is an interesting observation that was highlighted in the survey by a number of Asian respondents. Due to their low body weight they were ineligible to donate blood and therefore made ineligible to join the

ABMDR. The current system of donating blood to join the ABMDR is fundamentally discriminating against the Asian population since they tend to physically be of a smaller body build. The Asian population currently make up less than 3% of the ABMDR. “Be The Match” in the United States of America do not have a minimum weight criteria for joining their bone marrow donor registry, they follow donation medical guidelines and only exclude donors from joining if their weight is extremely low in comparison to their height.

Gay men are also excluded from donating blood and joining the ABMDR. Male donors are the preferred donors when searching for matches and by excluding the entire gay male population in Australia is another lost opportunity. In the UK gay men are allowed to join the bone marrow donor registry so there is no reason why Australia can’t do the same.

“I don’t know a lot about the ABMDR policy for donating however I would be more inclined to donate if sexuality isn’t a determinant.” – Friend of an ex-patient

“Fellow Salvadorans and other Latin American acquaintances reported that, on contacting the Australian Red Cross (blood service) to register, some were turned away at the point of identifying their ethnicity because it was feared they could be carriers of potential illnesses from their country of origin. As far as I know, neither the U.K nor the USA practice such restrictive requirements for signing up on to national bone marrow registers.” – Patient living in the UK

Considering the Red Cross Blood Service is the primary place in Australia where people join the Australian Bone Marrow Donor Registry, it is shocking to find that very little promotion of bone marrow donor recruitment exists within the blood service and in fact the total opposite occurs. Whether it’s due to a lack of understanding and knowledge of staff at the centres or the simple fact that bone marrow donor recruitment is not part of the blood service’s mandate, either way there is anecdotal evidence as seen in Appendix A that indicates joining the ABMDR through the blood service is difficult. As well as anecdotal evidence, one only needs to visit a Red Cross Blood Service centre to see that you may find only one brochure about the ABMDR amongst all the blood donation information, posters and campaigns at the centres. We appreciate and commend the blood service for the important work they do, however our aim is to improve donor recruitment strategies and it is necessary to review the way it operates since it is currently the only avenue for bone marrow donor recruitment.

Specific Recommendations

- 3.1 A question identifying people's ethnic heritage is added to the Red Cross Blood Service's blood donation questionnaire to identify potential ABMDR registrations.
- 3.2 Blood donors from ethnically diverse backgrounds and who meet ABMDR eligibility are offered information and directly asked if they wish to join the ABMDR through the blood service questionnaire.
- 3.3 Staff at the Red Cross blood service centres are trained to identify potential ABMDR donors by verbally providing information and opportunity to join. Training should be implemented immediately, especially if changing the blood donation questionnaire takes longer than 6 months to implement. UR the Cure has a resource kit that quickly and easily educates people about the ABMDR and the need for ethnic diversity and can be utilized as a basis to train staff.
- 3.4 Red Cross Blood Service eligibility should not prevent eligible, young and ethnically diverse people from joining the ABMDR.
- 3.5 Gay men who fit the required criteria (young and ethnically diverse) are made eligible to join the ABMDR.
- 3.6 More promotional materials and posters about the ABMDR are to be made easily available and visible at Red Cross Blood Service centres.
- 3.7 Specific Red Cross Blood Service centres located in ethnically diverse suburbs can be targeted to capture donors who fit the required criteria (young and ethnically diverse) and to be prioritised when implementing the above specific recommendations.

87% of all survey respondents believed that a question identifying a person's ethnicity should be added to the blood donor questionnaire to identify potential ABMDR registrations

Recommendation 4: Support and maximise patient drives as opportunities to drive diversification of the ABMDR

Rationale

Beginning with the ground breaking work of Shirley Nolan, who established the first bone marrow donor registry in the world in aid of her son Anthony Nolan, patient lead drives and activism has been crucial to driving bone marrow donation recruitment and processes forward.

Patient led drives and activism are key to improved diversity of the ABMDR because patient campaigns come with cultural expertise, links and reach that can drive registrations in under-represented communities.

The Australian Red Cross Blood Service and ABMDR's ability to support donor recruitment drives within the community and to provide innovative solutions is extremely limited. There are excellent overseas models for supporting community led action, such as 'The Stem Cell Club' five step model; an evidence based process for donor recruitment drives (Fingrut, 2015). "Be the Match" in the USA also provide valuable volunteer training.

"I have received training from Be The Match (in the USA) and I conduct drives with a group of volunteers. My volunteers and I have signed up hundreds of South Asian individuals in the US in the past year to the registry. It has been so difficult to do this in Australia!" – Brother of an Australian patient

The value of being able to conduct drives within under-represented communities has been consistently demonstrated in the high level of targeted registrations achieved by overseas campaigns such as #matchforlara and #registerforruby – both campaigns successfully found donors.

Support and funding for donor recruitment drives currently varies from state to state which gravely disadvantages patients living in certain states. For example Western Australia have been able to run drives which have registered over 120 people at one event which was supporting a young boy searching for his match. Versus South Australia

which currently do not have any ability or resources to do donor recruitment drives, much to the disappointment of 2 young mothers currently searching for their match.

“... since ABMDR staff must be present at the drives, we have had a really tough time getting them to come out to do drives within the community (Perth ABMDR was an exception)” – Brother of an Australian patient

Example of the need to support recruitment drives

Tania is a patient currently searching for her lifesaving stem cell match. In late 2016 the ‘Find Tan a Donor’ campaign had a Croatian community organisation willing to run a drive at a major event that was heavily attended by Australians with Southern European heritage (who makes up less than 4% of people registered on the ABMDR), however the Australian Red Cross Blood Service nor the Australian Bone Marrow Donor Registry were able to provide any mechanism for registration at the event.

To find out more about Tania and other patients currently searching for their stem cell match, please see Appendix B

“...my friends mobilized and partnered with DKMS and Anthony Nolan (UK bone marrow register organizations) to run bone marrow donor registration drives to find a Latin American donor for me. The drives were easy to organize as there was training available and registration required potential donors to simply swab their cheeks and provide a sputum sample. In contrast, I was dismayed that in Australia drives are more difficult to organize as they require more preparation so that a blood donation can be carried out first.” – Patient living in the UK

It is important that the ABMDR finds immediate solutions to better maximise the value of patient led drives, particularly when the drives are targeting the ABMDR’s priority population (young and ethnically diverse). It is extremely difficult for patients and their families to conduct their own search campaigns, particularly when experiencing distress and some simply don’t have the skills to do so. We need to better support those Australians with diverse ethnic backgrounds currently searching for a donor. Many feel they are simply told they need a lifesaving stem cell match and then are left completely on their own to “fend for themselves” whilst they wait months or years for their match. Please see Appendix C for further detail on patient experience during the search process and how this needs to be improved.

Providing improved support to patients and their families has benefits not only for their psychological well-being but also presents a great opportunity for the ABMDR to reach the targeted populations to diversify the registry.

“No patient or parent should be broken devastating news and then be told to go and find a match! Shameful really” – Parent of a patient searching for their match

Specific Recommendations

4.1 The mandate of the proposed new structure in recommendation 1 must support and maximise the value of patient led recruitment campaigns to improve diversification of the ABMDR.

4.2 Support should include provision of structured resources, tools, templates and training for the community led campaigns and provide connection links to overseas donor recruitment organisations.

4.3 Proactive donor recruitment drives to be consistently run in young and ethnically diverse communities.

4.4 The above specific recommendations are to be practiced in all states and territories.

86% of all survey respondents believed that more support is needed for patients searching for their match and their search campaigns

85% of all survey respondents believed that proactive donor drives should be made available in all states and territories

Recommendation 5: Design and implement awareness and education programs targeted at ethnic and indigenous communities to proactively promote people joining the ABMDR

Rationale

Currently there is very little to no awareness or education about the ABMDR, how to join, what's involved if you are a match and other important key messages. Awareness and education is currently driven by patients and their family/friends desperately searching for a lifesaving match. This is reactive and many patients are going to extreme lengths to educate their networks since there is no organization or group currently doing-so. Many patients run their own Facebook campaigns (if they have the skills to do so), involve themselves in national and international media campaigns, create short films, seek out support from overseas organisations and even meet with overseas Presidents pleading with them to help their cause. This has been the case in Australia for over 20 years with very little improvement or change.

"I was the first adult in Australia to receive a cord blood bone marrow transplant, because they could not find an adult match in Australia or around the world" – Ex-patient who has an Asian background and couldn't find a stem cell match over 20 years ago

Proactive donor recruitment drives, awareness and education campaigns need to be implemented by the proposed new structure in recommendation 1, which will ensure that the correct information is being disseminated to the public and to the appropriate community groups (young and ethnically diverse).

Information made available to potential donors is currently overwhelming. The ABMDR donor brochure is translated into several languages which is fantastic, however the information needs to be simplified and less text dense. A better marketing approach to captivate the audience is to provide basic key educational messages in a simple one page document (or a small number of pages depending on the format and page size of the brochure). It needs to be well-designed with more pictures and diagrams and needs to be visually appealing to the audience. The detailed information can be referred to and accessible to those who wish to find out more.

82% of all survey respondents believed that information about the ABMDR needs to be provided in an easy to read format

Making information available online and through social media is also crucial to engage the younger population. With the rise of the smart phone and a digital world, it's extremely important that awareness and educational messages are promoted online and in an engaging way. According to the Australian Communications and Media Authority, 88% of teenage internet users go online more than once a day.

Specific Recommendations

- 5.1 Proactive awareness and education about the ABMDR and key educational messages are targeted to young and ethnically diverse populations.
- 5.2 A revision of ABMDR materials and information for donors to simplify the message and better engage the audience. Consumer's input is obtained and utilized.
- 5.3 Implement educational programs for Year 12 students at high schools located in ethnically diverse suburbs as avenues to promote awareness and key educational messages. Please note; the Red Cross Blood Service already runs a "Youth Ambassador Program" in high schools so a similar program can be adapted related to bone marrow donor recruitment.
- 5.4 Utilize higher education networks in ethnically diverse suburbs as avenues to promote awareness and key educational messages. The Gift of Life America run a comprehensive "Campus Ambassador Program" which has successfully recruited 61,079 people to their bone marrow donor registry since it started in 2015.
- 5.5 Use social media and the online environment as a medium to promote awareness and education about the ABMDR.
- 5.6 Use cases of real patients searching for a stem cell match in communications and campaign materials to help drive action.
- 5.7 Connect and network with influential and community leaders to drive awareness and education campaigns and donor recruitment within their ethnically diverse communities. Consider partnering with organisations like the Cancer Council Victoria who have established networks within these communities as part of their "Cultural Diversity Plan"
- 5.8 Empower the many passionate people in Australia to promote awareness and education about the ABMDR to drive donor recruitment and support them with the training and tools required as mentioned in recommendation 4.

88% of all survey respondents believed that awareness and education programs need to target ethnic and indigenous communities to proactively promote to and encourage people to join the ABMDR

Recommendation 6: Improve transparency and accountability of ABMDR diversification and performance

Rationale

There is very little data about the ABMDR's performance in relation to diversification of the bone marrow donor registry via the website, annual report or through any other means.

Diversification of the registry is a health equity issue and it is important that the organisation be transparent and accountable in relation to its performance in strengthening diversity.

Transparency and accountability will also be important to measure the effectiveness of recruitment drives, awareness and education campaigns. This information needs to be easily accessible, particularly for the structure in recommendation 1 to be able to see how their activities are directly impacting the donor numbers and diversity on the ABMDR.

Donor recruitment organizations overseas regularly practice this. For example "Be The Match" which is run by the National Marrow Donor Program in America provides summaries of their board meeting minutes and outcomes data about donors and patients, which are made available to researchers and the public.

Specific Recommendations

6.1 The ABMDR routinely publically report the level of diversity on the registry, disaggregation of recruitment figures by ethnicity, age and patient outcomes

6.2 The data reported via these measures be used to inform recruitment strategies and investment

Conclusion

Thank you again for the opportunity to provide feedback to the review of the Australian bone marrow transplant sector. If you require any clarification or further information, please do not hesitate to contact Pamela Bousejean on 0416 047 807 or email info@urthecure.com.au

Pamela is willing to meet and further discuss the recommendations and how UR the Cure can be involved and support future recruitment strategies. UR the Cure has built an extensive network with patients, families, health professionals, hospitals and other not-for-profit organisations and has, to the best of its ability and within its available resources, already begun implementing some of the recommendations in this submission.

It is necessary that Australia “catches up” to the rest of the world and follows in the footsteps of overseas organisations who have been achieving success for many years. The changes we need are heavily supported by the Australian public as seen through the hundreds of respondents from the survey conducted by UR the Cure.

“I’m the president of the Katelyn Bedard Bone Marrow Association in Windsor, Ontario, Canada. We formed our association 11 years ago to make positive changes to the bone marrow registry in Canada. Many of the changes you are advocating for we have seen in Canada over the past 11 years. Best of luck with your campaign!” – President of the Katelyn Bedard Bone Marrow Association, Canada

UR the Cure believes that creating a structure focused on and responsible for diverse donor recruitment which has the ability to fundraise is the key to improve Australia’s future recruitment strategies. Doing-so will help achieve and support the implementation of cheek swab technology; maximise the opportunities to recruit ethnically diverse bone marrow donors through the Red Cross Blood Service; maximise patient drives to diversify the ABMDR; proactively promote to and educate the target young and ethnically diverse communities and enable the measurement of the effectiveness of its activities with the use of transparent and readily available data about the number and diversity of people joining the ABMDR.

Yours sincerely,

Pamela Bousejean (founder of UR the Cure)

References

Australian Red Cross Blood Service 2017, *Youth ambassador program*, retrieved 28 April 2017

<www.donateblood.com.au/red25/youth-ambassador-program>

Anthony Nolan 2017, *Who can join the register*, Anthony Nolan, retrieved 29 May 2017,

<<https://www.anthonynolan.org/8-ways-you-could-save-life/donate-your-stem-cells/who-can-join-register>>

Be The Match 2017, *Medical guidelines when you match a patient*, National Marrow Donor Program – Be The Match Registry, retrieved 27 May 2017, <www.bethematch.org/support-the-cause/donate-bone-marrow/possible-match/medical-guidelines-when-you-match-a-patient>

Be The Match 2017, *Weight guidelines when you match a patient*, National Marrow Donor Program – Be The Match Registry, retrieved 27 May 2017, <www.bethematch.org/support-the-cause/donate-bone-marrow/possible-match/weight-guidelines-when-you-match-a-patient>

Bosso, B, *Introduce cheek swab testing to increase bone marrow/stem cell donors in Australia*, Change.org 2016, retrieved 29 May 2017, <<https://www.change.org/p/australian-government-hon-sussan-ley-mp-australian-bone-marrow-donor-registry-introduce-cheek-swab-testing-to-increase-bone-marrow-stem-cell-donors-in-australia>>

Cancer Council Victoria, *Culturally Diverse Communities*, retrieved 27 April 2017

<www.cancervic.org.au/about/culturally-linguistically-diverse-communities>

Fingrut, W, Rikhraj, K, and Parmar, S, *Securing Informed Consent at Stem Cell Drives: An Implementation of World Marrow Donor Association Guidelines*, Conference poster, Stem Cell Club

Fingrut, W 2015, 'The Stem Cell Drive: A Canadian Perspective', *American Society of Hematology – Blood*, vol. 126, no. 23, pp 5434, retrieved 29 May 2017, <http://www.bloodjournal.org/content/126/23/5434>



Gift of Life Marrow Registry 2017, *Campus Ambassador Program*, Gift of Life, retrieved 28 April 2017
<<https://www.giftoflife.org/dc/cap1>>

Gift of Life Marrow Registry 2017, *About speed swabbing*, Gift of Life, retrieved 31 May 2017
<<https://www.giftoflife.org/page/content/about-gift-of-life-speed-swabbing>>

GN Samuel, IH Kerridge, M Vowels, A Trickett, J Chapman and T Dobbins, 2007, 'Ethnicity, equity and public benefit: a critical evaluation of public umbilical cord blood banking in Australia', *Bone Marrow Transplantation*, vol. 40, pp 729-734

Health Resources and Services Administration 2017, *National Marrow Donor Program, a Program Contractor*, U.S. Department of Health and Human Services, retrieved 26 May 2017,
<<https://bloodcell.transplant.hrsa.gov/about/contractors/nmdp/index.html>>

Appendix

Appendix A: Anecdotal evidence from the survey of people's experiences when trying to join the ABMDR

Please note, quotes regarding people's ease of joining the ABMDR have not been purposely excluded. There were no quotes that mentioned how easy it was to join the ABMDR.

"My friend went into donate blood, and was disappointed when they did not ask her if she wanted to be on the bone marrow (donor) register, she had to ask if she could. (She is of) Maltese back ground" – Patient currently searching for a match

"I called to go on the bone marrow (donor) registry and had to jump through hoops to get an appointment. If I wasn't motivated to do it for personal reasons I would not have persisted" – Friend of a patient currently searching for a match

"I was very disappointed that I wasn't asked to register to be a bone marrow donor, I had to ask to register and felt as though the staff at Red Cross (blood service) couldn't be bothered with the extra paper work!" - Friend of a patient currently searching for a match

"Have now joined the bone marrow (donor) registry. Took 2.5/3hrs at blood centre" – Supportive member of the public

"I've been a blood donor for many years and I only found out about the BM registry (Australian Bone Marrow Donor Registry) through FTAD (Find Tan A Donor Campaign). When I made the appointment I advised them I wanted to go on the registry. I had to remind them again when I turned up for my appointment and again when they started taking my blood" – Supportive member of the public

"Tried to join the bone marrow donor registry from a mobile donation unit and was told they can only do it from permanent clinics." – Supportive member of the public

"I've donated blood for around 30 years & only knew about the register (Australian Bone Marrow Donor Registry) when my son was diagnosed with ALL (Acute Lymphoblastic Leukaemia)" – Family member of a patient

"I asked my local Red Cross Blood Service for an (ABMDR) registration form, they promptly gave me one but weren't confident in answering questions, instead referring me to the ABMDR. And yet they have asked me on several occasions about donating plasma." – Supportive member of the public

"Unfortunately it (the ABMDR) has come to my attention because my friend's son has cancer but I should have been aware before when donating blood" – Friend of a patient

"It should be a question asked on the form when you donate blood at the Australian Red Cross (blood service). I had to ask and there wasn't much knowledge about it." – Friend of a patient

"There is not much information out in the foyer or on the front desk area (at the Red Cross Blood Service Centre) relating to it (the ABMDR). Why is that?" – Family member of a patient

"I asked years ago (about the ABMDR) and was told (at blood donation) that other people had to do that (add me to the ABMDR) and involved a 'lot of work' and they were not sure if I was too old" – A patient's blood donation experience before they fell ill

"I had to ask to join the ABMDR and the Red Cross (blood service) nurses didn't really know much about it to give me accurate information" – Supportive member of the public

"I could not even find a brochure about bone marrow donations last time I was there (at the Red Cross Blood Service)" – Family member of a patient



“Red Cross (blood service) have always been very good but generally only concentrate on blood products as that is their primary concern - bone marrow has always been an afterthought.” – Family member of patient

“I have donated blood many times over the years and have never once even thought to become a bone marrow donor as it was never mentioned” – Family member of a patient

Appendix B: Patients currently searching for their lifesaving stem cell match



Tania with her 2 children and husband

Tania is from Adelaide and was diagnosed with Acute Myeloid Leukaemia in July 2016. Tania can no longer undertake chemotherapy as a form of treatment and needs a stem cell transplant as her chance for a cure. Due to her Southern European heritage, Tania has been struggling to find her stem cell match.

With the support of family and friends, Tania has launched a Facebook campaign, “Find Tan A Donor” who have given away prizes such as televisions and holidays in an attempt to encourage people to join the ABMDR.

Her story has appeared in newspaper articles and on Channel 10’s Television program, “The Project”



Kate with her children Asher and Isabella and husband, Simon

Kate is from Adelaide and was diagnosed with Acute Myeloid Leukaemia in July 2016. She is a young mother of 2 and needs a stem cell transplant as her chance for a cure. Due to her Hungarian heritage, Kate has been struggling to find her stem cell match.

Kate’s story has been shared through the media. She also runs her own Facebook campaign as best she can in between hospital visits and treatment - “Help Kate Find A Bone Marrow Donor”.

Kate is “very troubled by the lack of promotion of the (bone marrow donor) register in Australia”.



Melissa with her children Madeleine and Sebastian

Melissa is from Melbourne and was diagnosed with Hodgkins Lymphoma in June 2013. She is a young mother of 2 and needs a stem cell transplant as her chance for a cure. Due to her Italian heritage, Melissa has been struggling to find her stem cell match.

Melissa has received various forms of treatment including targeted therapies to keep the cancer under control while she waits for her lifesaving match. Targeted therapies are extremely expensive, at \$10,600 per cycle, the single mother of 2 has had to fundraise to keep herself alive while she waits for her lifesaving match.



Jake has been searching for his lifesaving stem cell match for many years now

Jake is a young 14 year old boy from Perth. He has a rare form of blood cancer called Chronic Myeloid Leukaemia. He was diagnosed in July 2013 and needs a stem cell transplant as his chance for a cure. Due to his Samoan heritage, Jake has been struggling to find his stem cell match.

Jake's Mum, Renee has been campaigning for years through the "Jake's Quest For A Cure" Facebook campaign. They have travelled to New Zealand to engage with different organisations over there and have been involved in advertising campaigns.

Appendix C: Patient experience and the need to strengthen “person-centredness”

The “Find Tan A Donor” campaign have highlighted the difficulties patients face when they are told they need a stem cell transplant as a chance for a cure. UR the Cure along with the Find Tan A Donor campaign believe patients need to be better supported through this time through the following ways:

1. Establish a central contact person for each patient who acts as the primary liaison and who helps the patient navigate the system appropriately from diagnosis to transplant. The central contact person needs to support patients to access appropriate information in a timely manner. Working in partnership with health services who provide similar services to improve patient-centred care may be beneficial, such as Queensland Health's recently established 'Nurse Navigators' <https://www.health.qld.gov.au/nmoq/optimisingnursing/nurse-navigators>
2. Principles of person-centred healthcare be built into the bone marrow recruitment and patient support processes, including taking a co-design (Waitemata District Health Board, 2010) approach to programs, services and initiatives. Australia is already working to build a person centred health system, the reason for this is highlighted in a discussion paper by the Australian Commission on Safety and Quality in HealthCare (ACSQH) which states:

“Recent research has shown that there are many benefits to patient-centred care, broadly categorised as care experience, clinical and operational benefits. Studies show that when healthcare administrators, providers, patients and families work in partnership, the quality and safety of health care rises, costs decrease, and provider and patient satisfaction increase”. (ACSQH, 2010)

3. Develop easy to read explanations of the search process that answers common questions such as how often the search is refreshed, what is automated, what is done by staff, what is the role of the treating doctor versus the search coordinators and so on. Ensure Health Literacy standards are met when developing the information.
4. The membership of the ABMDR board be reviewed to strengthen ethnic and indigenous diversity and patient representation. One board member has lived experience as a donor, it is unclear if any members have lived experience as a bone marrow donor recipient.

Feedback collected in support of UR the Cure's submission suggests that the care experience of patients searching for their stem cell match should be improved. Patients reported finding the search process confusing and they do not have a clear liaison point which leaves them feeling unsupported and un-informed. Patients also spoke of improved support and clarity as critical to improving their wellbeing because the prolonged wait and ongoing treatment is already extremely physically and emotionally stressful.

"I was on the phone with the hospital search coordinator who mentioned in passing "now that we have a donor for you...". I was so shocked I had to ask her to repeat herself - she assumed my doctor had told me that a donor had been found but no one had yet contacted me. I found out via her mentioning it in the course of another conversation that I now had a shot at living". - Ex-patient

"It's funny because what it says will happen on the ABMDR website about getting given the details of the coordinator, being contacted to look into family history etc does not appear to happen. My Dad spoke with the coordinator in our state to confirm if they are searching and she told him he had to call the Red Cross Blood Service to check. They then told him to call the ABMDR, who said to call hospital. But my doctor said whilst she initiates the search she is not involved in or aware of the searching process which then occurs. It's getting very frustrating. It seems a shame when DKMS is so clearly involved and informative." – Current patient

"I was getting very anxious about what was happening with the search. The counsellor I was seeing suggests that getting more information about how the search process worked would be helpful for me to manage my anxiety. When I contacted my search coordinator for information on how the search worked I was told she could not legally speak to me due to her role as both a donor and search coordinator and that I should talk to the transplant physician or transplant hospital coordinators. I had no details for the hospital coordinators and had not yet had interaction with this hospital, I had met the doctor once but was told he was on extended leave. I just wanted to know how the search worked, but no one could really clearly tell me". – Current patient

"Whilst running the campaign we just got so many suggestions on trials and treatments. I think it's really common for patients running campaigns to get bombarded with information. It is hard to know what information is worth asking the Doctor about, how to ask it in the right way and which information to ignore". – Current patient



The cure to some cancers is in your body. You just need to join the Australian Bone Marrow Donor Registry to be searched and found.

You are the “UR” in the “CURE”

