

Save Our Swabs

UR the Cure Survey and Petition

Improving ethnic diversity on the Australian & worldwide stem cell registries



Education

Awareness

More lifesaving matches



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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 registered on the Australian Bone Marrow Donor Registry (ABMDR) through awareness campaigns and targeted education programs. UR the Cure also advocates for changes in Australia's system to make it easier for people to join the ABMDR and to save lives. UR the Cure has been a major partner in the Strength to Give Project with over 1000 people directed to the Strength to Give website, enabling 710 new online registrations since September 2019. UR the Cure also ran its own recruitment drives and facilitated and supported others in the community to run drives, with 65 people completing a swab (confirmed) and 71 unconfirmed (first version of kits provided for drives were non-traceable kits).



Introduction

In April 2020, UR the Cure launched the “Save our Swabs” survey and petition to gain more insight into people’s experiences with the Strength to Give program. 280 people from a variety of different backgrounds, responded to the survey, including patients and their loved ones, health professionals, supportive members of the public, people who have joined the Australian Bone Marrow Donor Registry (ABMDR) either through a cheek swab or blood sample, as well as people representing local and international organisations.

The survey asked a number of direct questions;

- How strongly do you agree with the following statement? “Cheek swab testing needs to continue in Australia as a way for people to join the donor registry”
- Do you believe the Red Cross Lifeblood service is effective enough on its own to recruit people onto the donor registry (without a cheek swab program)?
- If you are a patient/ex-patient or a family member or friend of a patient/ex-patient, what does it mean for you to have something like the Strength to Give cheek swab program available?

The survey also provided the opportunity for people to elaborate and add their comments.

UR the Cure ran a similar survey in 2017 regarding improving the donor pool and this report will also comment on 2 change.org campaigns completed in support of the continuation of cheek swab testing in Australia.



Executive Summary

The Australian public demonstrated it strongly supports the continuation of the Strength to Give program and believes it is important that we rely less on overseas donors and grow our Australian donor pool. As one family member comments, “We don’t rely on overseas organisations for our local blood supply and it needs to be the same for stem cell donors”.

The data from the 2020 “Save our Swabs” Survey demonstrates that 95% of the 280 respondents agreed that cheek swab testing needs to continue in Australia as a way for more people to join the donor registry as a way to increase the number of lives saved.

95% of survey respondents agreed that cheek swab testing needs to continue as recruitment method in Australia

The sentiments and commentary from the current UR the Cure “Save Our Swabs” survey strongly resemble the commentary obtained from the UR the Cure 2017 survey regarding the challenges of joining the ABMDR. In 2017 over 500 people responded and described a range of factors experienced regarding the difficulty of joining the ABMDR via Red Cross Lifeblood including the lack of available information, lack of focus on recruitment for the ABMDR, confusion regarding eligibility and being provided with conflicting advice. Comparing comments from both surveys indicate that there has been no change since 2017, and that Red Cross Lifeblood (currently the only place Australians can join the ABMDR) is not effective in recruiting stem cell donors. Please refer to Appendix A for anecdotal evidence gathered in the 2017 survey.

“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

Over 1300 people have signed change.org petitions in recent times. The Australian Marrow Match group conducted a change.org petition which received 800 signatures in support of the continuation of cheek swab testing in Australia. In addition another change.org petition was conducted in 2017 by Bianca Bosso, whose mother has unfortunately since died from blood cancer while waiting for a donor. This petition gained 500 signatures in support of cheek swab technology to grow the donor registry.

UR the Cure with the support of the public strongly urge the ABMDR and the government to work together to take the positive step forward that Australians have waited so long for and to continue the cheek swab Strength to Give program.



Anecdotal Evidence – People’s experiences at Red Cross Lifeblood

93% of survey respondents believed that Red Cross Lifeblood is not effective enough on its own to recruit stem cell donors

Quotes from survey respondents related to awareness, general promotion issues and recruitment of stem cell donors by Red Cross Lifeblood

“People do not know ABMDR even exists, plus there is very little advertising. Even people who regularly donate blood are unaware.” *(Family member or friend of patient/ex-patient)*

“I regularly give blood and I haven’t been asked or told about the registry for some time. I am familiar with the cheek swab process via urthecure through their online presence.” *(Someone who completed a cheek swab)*

“The blood donor needs to be well informed to ask for the service (to join the bone marrow donor registry). It is not something that is openly offered or promoted. It is not an easy way of joining the registry.” *(A family member or friend of a patient/ex-patient)*

“They do an awesome job of collecting blood but nowhere on that form that you are asked to fill out before donating blood do they explain that so many people need a bone marrow transplant and by joining the register is their only hope of finding a donor. I don’t mean pester them to join, just ask if they would consider it”
(Family member or friend of a patient/ex-patient)

“The blood service don't always promote the register to donors and have a number of times told lifeblood centres to slow down on recruiting bone marrow donors due to workload.” *(Family member or friend of a patient/ex-patient)*

“Until we went through needing a Stem cell/Bone Marrow Transplant, I had no idea about the Bone marrow registry” *(Family member or friend of a patient/ex-patient)*

“There is not enough knowledge through the blood banks. When I called up the Red Cross, the person I spoke to didn’t give me the correct information about bone marrow” *(Family member or friend of a patient/ex-patient)*

“Eligible, existing blood donors are not informed of the stem cell donation process when giving their blood



donation - this is missed opportunity!" *(A family member or friend of a patient/ex-patient)*

"Most of the posts on their social media page are about donating blood which is great however there needs to be more awareness about donation of bone marrow which they don't do much of. In order to get a diverse group of young healthy people on the registry there needs to be a lot of awareness on social media platforms to spread the word." *(A family member or friend of a patient/ex-patient)*

"I have donated blood before but prior to being diagnosed with Leukaemia I had never heard of stem cell transplants / donors and never knew there was a need for it. I am grateful to have found a donor for my upcoming transplant on the Australian register, but many others aren't as lucky." *(A patient/ex-patient)*

"I'd never heard of the bone marrow registry until the (cheek) swab program was advertised" *(Family member or friend of a patient/ex-patient)*

"When I was a blood donor, (before I got leukemia), I didn't even know about the donor registry" *(A patient/ex-patient)*

"More public awareness and campaigns for bone marrow donors needs to happen. Everyone I talk to thinks that you can only donate blood at the Red Cross not register to be a bone marrow donor." *(A patient/ex-patient)*

"I have never seen any information come out from Red Cross about this register and when my broader family went to be tested when I was diagnosed with AML, they were not informed well at all about any processes or even told if they were a match for me (they weren't). The communication was terrible." *(A patient/ex-patient)*

"I feel like Red Cross Lifeblood has done no advertisement or promotion to support the donor registry. There has been no clear message of the association between the two." *(A family member or friend of a patient/ex-patient)*

"I don't think people are given enough information about this or educated about how important this all is to blood cancer." *(Family member or friend of a patient/ex-patient)*

"For a start there needs to be more awareness and general knowledge and information for the public!!! If it helps to save the lives of people with blood cancer of course it (Strength to Give) is important to remain!!" *(Family member or friend of a patient/ex-patient)*

"Not enough marketing exposure. People's fear of needles. Limited to fix location where it can be done" *(A family member or friend of a patient/ex-patient)*



"I actually registered with them (Red Cross Lifeblood), but unfortunately they were not really that helpful? (for lack of the right word). The impression that I got at the time was it was an inconvenience." *(Someone who is thinking about joining the donor registry)*

"There is also no encouragement from staff to sign up, no marketing material or visuals in the Centers. The biggest issue though is that the program is opt in, when people come to donate blood, marrow sampling should be on an opt out basis."

"Australians do not know about the bone marrow donor registry .. & if they do think it is a painful biopsy. Many people will die without this (Strength to Give) service." *(A patient/ex-patient)*

"I donate plasma / blood regularly and have never been asked to join the bone marrow donor registry! I found out my friend needed bone marrow and realised I wasn't on the registry. The lady who took my blood test commented she couldn't remember how to do it because she hadn't done one in a long time!" *(Friend of a patient/ex-patient)*

"I have donated blood for a long time but never heard of bone marrow registry until the strength to give campaign." *(Health professional)*

"Until I became a patient, I was totally unaware. I am reasonably switched on to things happening in society. So it is also reasonable to assume there is little knowledge of it in the general population." *(Patient/ex-patient)*

Quotes from survey respondents related to accessibility issues of the Red Cross Lifeblood Service

"While Red Cross does a wonderful job, there is a vital need to reach out into communities who wouldn't normally use Red Cross services. There is a need to reach out into these communities of different nationalities and cultures" *(Family member or friend of a patient/ex-patient)*

"My own family member needed a stem cell donor urgently after failing to respond on conventional Leukaemia medication, however we were told she did not have a match internationally after all of the databases were searched. She is Middle Eastern and does not fit the typical bone marrow match mold of 'white Caucasian'. We contacted the Australia Red Cross to see if we could urgently arrange for a blood bank vehicle to come to our local Parish so we could get as many donations as possible. We were told that due to a lack of resources that their blood bank vehicle was unavailable for 9 months. We felt defeated and hopeless. Until we found Ur the Cure. They make



it possible to obtain as many swabs as possible in the most quick, accessible, safe and efficient manner” *(Family member of a patient/ex-patient)*

“Many socially, culturally and financially disadvantaged people in the community who cannot take time off to attend blood banks, or cannot arrange transport to get there and back with a support person are not able to be enlisted” *(Family member or friend of a patient/ex-patient)*

“I believe there needs to be other ways to recruit donors and continue to add to the register. Other services gain access to a different cohort of people.” *Family member or friend of a patient/ex-patient*

“I am well aware of the importance of donating blood thanks to the Red Cross service but had no idea about the need for bone marrow donors from their efforts. The process of having to book an appointment, travel to the appointment and spend hours there compared to spending 10 mins preparing cheek swabs mailed to your home is a huge accessibility issue” *(A family member or friend of a patient/ex-patient)*

“People find it hard to go to Red Cross when open. I live in a regional area and can’t get to the Red Cross, the testing needs to be mobile. When my son and a neighbor needed bone marrow the whole community wanted to get tested. Sporting groups doing testing nights in their very own halls. This makes so much sense and enables others to do something they never have, a simple swab.” *(Family member or friend of a patient/ex-patient)*

“What about the people who are unable to donate blood? What about the people who live too far away? What about the people who are too busy? This simple kit ensures ANYONE can access it and complete it during their own time, in the comfort of their home.” *(Family member of a patient/ex-patient)*

Quotes from survey respondents related to eligibility issues of the Red Cross Lifeblood Service

“There are too many people who are excluded from giving blood” *(Someone who completed a cheek swab)*

“Not everyone can or will donate blood so we need to widen the audience and a cheek swab is a quick and pain free way to do this” *(Family member or friend of patient/ex-patient)*

“People like me can’t donate blood so I would never go there.” *(Family member or friend of a patient/ex-patient)*

“A decent proportion of Australia's population were born overseas and are ineligible to give blood (like myself) -



they want to help, but they were not aware of this avenue because they do not visit blood donation centres.”
(Someone who is thinking about joining)

“The current method for registering to become a stem cell donor via the Australian Red Cross Blood Service is flawed. Donors still need to go through the Red Cross Blood Service which excludes potential blood donors. For example gay healthy men in long term relationships though eligible to the AMBDR, are not eligible if they try to register through the Red Cross Blood Service.” *(Someone who competed a cheek swab)*

“Many people who simply want to join the ABMDR but don’t meet whole blood donation criteria are turned away from Lifeblood when they would still be eligible for stem cell donation.”

“I have many friends who give blood, but were not on the registry as they have not been asked. Many categories may be unable to give blood - travel overseas and new tattoos etc, but they are able to be on the donor registry. Unfortunately not everyone gives blood, yet many would donate stem cells if they got the call.”

“Over 1.3m UK ex pats live in Australia, many who are barred from giving blood due to CJD. Swab kits completely negate this problem and open up a wider pool of potential donors with a diverse heritage, to help increase numbers, diversity and resolve the problem.” *(Founder of 10,000 Donors Down Under)*

“We are missing a large percentage of the population due to blood donation ineligibilities...eg blood cannot be donated if you’ve had a recent tattoo, lived in UK for a specific period, gay/lesbian restrictions etc. These do not apply to stem cell donation.” *(A family member or friend of a patient/ex-patient)*

Quotes from survey respondents related to convenience issues of the Red Cross

Lifeblood Service

“You have to make an appointment to go in, donate blood, then ask to be on the register. Time off of work and the inconvenience of it all. Young males make better donors, females are usually the ones to go to this effort. It’s just too time consuming. Weekend appointments are often full” *(Patient)*

“It has to be made easy for people to register and get tested for matching. The more hurdles you put in front of people, the easier it is for them not to go ahead.” *(Family member or friend of a patient/ex-patient)*

“Only the very small percentage of proactive, altruistic of people will make the effort to go to the blood service, and proactively ask to give blood to join the stem cell registry.” *(Founder of 10,000 Donors Down Under)* “It doesn’t



allow convenience like the swab kit does or doesn't require an appointment in work hours." *(A patient/ex-patient)*

"It is clear that cheek swabs are a far more convenient, donor friendly option to join the register. They are exceptionally more accessible than having a blood test via Lifeblood."

"I'm a mother of a baby, it's incredibly difficult for me to leave my child for that long and organise to go and dedicate such a long time to donating blood."

"People may feel pressured to be blood donors when they may just want to donate their bone marrow. Not donating blood shouldn't preclude them from becoming stem cell donors!" *(Patient/ex-patient)*

"It is a much slower and a much more invasive process. And whilst you don't need to donate blood to be on the register it is hard to convince the Red Cross to just let you go on the register without giving blood."

"Not enough people are donating blood to begin with, let alone registering as a stem cell donor via the Red Cross Lifeblood service." *(Family member or friend of a patient/ex-patient)*

General Quotes from survey respondents about Red Cross Lifeblood

"For the option of registering solely via Lifeblood to be effective, blood donors would need to be actively engaged to join the registry as part of their usual donation (or as an extra step to this)." *(Research Fellow - Sustaining and Understanding Living Donors Research Program, The University of Queensland and Lead Researcher and the Donor Research Network)*

"When volunteers donate blood, joining the bone marrow registry should be an opt out rather than opt in process. Many blood donors don't understand the process." *(A family member or friend of a patient/ex-patient)*

"The Red Cross service is definitely not an ideal solution in these changing times." *(Patient)*

"Not enough people are registering. The Red Cross Lifeblood is flat out providing a blood donation service." *(A patient/ex-patient)*

"The service is full of bureaucratic red tape, the process is cumbersome and time consuming. When filling out the forms it does not encourage people but has a scary undertone. Where in reality most of the donors will never be called up and if so the process is not painful at all." *(A family member or friend of a patient/ex-patient)*

Anecdotal Evidence about Strength to Give

General Quotes from survey respondents about Strength to Give

“The evidence suggests that the easier it is to join the register, the more likely people will be to do it, especially if it is accessible to them at home and doesn't require a trip to a donor centre and a blood donation in order to join. For that reason, and to make registering accessible to the people who most need to join (male, young, from different ethnic backgrounds), it is absolutely vital the cheek swab testing continues. Cheek swabs are essential - the strong response of Australians in helping to meet the 5,000 target of Strength to Give in a short time-frame should be clear evidence of that.” *(Research Fellow - Sustaining and Understanding Living Donors Research Program, The University of Queensland and Lead Researcher and the Donor Research Network)*

“This is by far the most effective way to get people on the registry. The old method simply didn't result in enough people but cheek swabs have been massively successful.” *(Australian Red Cross Lifeblood's Chair of Donor Research, The University of Queensland and Lead Researcher and the Donor Research Network)*

“The amount of people that can get registered with the use of the swabs, who do not have access to the Red Cross service is increased, as well as the ability to conduct swabs in more locations like offices, shopping centres, multicultural and religious gatherings. Also, through swabs it does not restrict those who have spent some time living in the UK, like the restrictions that the Red Cross does.” *(Patient)*

“Everyone deserves an opportunity to be saved. The more people who swab the more options we have to save others.” *(Someone who completed a cheek swab)*

“People are time poor but love to help. Something simple will be far more successful” *(Family member or friend of a patient/ex-patient)*

“Australia needs to do better to grow our donor pool, and cheek swab testing is the only effective way to grow this donor pool”. *(Family member of a patient searching for a stem cell match)*

“In a world which is currently changing rapidly, cheek swabs sent directly to your home are the future. *Family member or friend of a patient/ex-patient)*

“Cheek swabs are needed. In the USA, we have them mailed to our house and without this key aspect our registry would not be as large...ultimately allowing people to die. *(Supportive member of the public from the USA)*



“Cheek swabs are the easiest and most cost-efficient way to collect bone marrow donor samples. They can also be used in live drives where patient's and their families can hold drives to gather more donors.” *(Family member or friend of a patient/ex-patient)*

“Please help fund this amazing initiative.” *(Family member or friend of a patient/ex-patient)*

“We should be making it as simple as possible for people to be placed on the donor register - people are generally good and want to help, but they also want to put in as little effort as possible” *(Someone thinking about joining)*

“I am a health professional and family member of a patient and the response we have had has been amazing when we put out the call for family members to register. Having the cheek swabs available made it so much easier for people to participate & register.” *(Health professional and family member of a patient)*

“This is working exceptionally well elsewhere in the World. For example, DKMS in Europe, have 8 million potential donors signed up on the registry and have given 69,000 people with blood cancer a second lease of life through a stem cell match. Swab kits are clearly working.” *(Founder of 10,000 Donors Down Under)*

“An example of where this has worked in the UK is www.10000donors.com which have signed up 45,000+ new unique donors onto the registry, and found 14 confirmed matches to save peoples lives.” *(Founder of 10,000 Donors Down Under)*

“Strength to Give in Australia is a game changer and real chance for Australia to make a difference. We are currently behind the rest of the world in this area.” *(Founder of 10,000 Donors Down Under)*

“The cheek swabs are a lot easier for people to do. People need a quick and simple way to join especially those who work full time” *(A supportive member of the public)*

“Cheek swabs have proven to be an easy and effective method of registration. It is non invasive and people are very willing to donate. It cant be any easier!” *(A family member or friend of a patient/ex-patient)*

“As a hospital pharmacist I understand that accessibility to health services is a huge factor in how well they function. The cheek swab program is extremely accessible (5 mins at home) and I strongly believe will result in a much larger number of people joining the registry.” *(Family member or friend of a patient/ex-patient)*

“Having a robust donor list that equitably represents our country's diversity is essential to public health. Please continue cheek swabs - they contain the answer to curing many cancers & this should never be overlooked or undervalued.” *(A patient/ex-patient)*



“As an ex-patient alive today due to a bone marrow transplant, the cheek swab program allows me to promote the registry via a quick, easy and accessible measure - far, far easier, more accessible, quicker than the blood-sample method that I have had limited success in promoting, despite my personal story.” *(A patient/ex-patient)*

“Strength to give has also increased public awareness of stem cell transplants” *(A friend of a patient/ex-patient)*

“I work in a bone marrow / stem cell transplant unit and see first hand how important it is for Australians to be on the registry. So many patients struggle to find a donor.” *(A health professional)*

“Australia needs to build a solid database of potential donors, ensuring a large pool of candidates reflecting the genetical diversity within its population. This is essentially a no brainer and successful examples of other countries like the USA or Germany prove it. *(A family member or friend of a patient/ex-patient)*

“By doing away with the need of specialised staff (e.g. phlebotomist) from the Red Cross Lifeblood service, cheek swab brings the freedom to conduct drives outside the normal working hours *(President of Healing Inc)*

“This method is suitable and of practical use in community drives where trained volunteers can easily help in the recruitment drives. *(Dr. Amal Bishara)*

“I worked in the Hadassah Registry in Jerusalem for more than 10 years, in these years I established the Arab Donor Project. I started on 2008 from 130 Arab donors on the registry and left in 2018 with more than 37,000 recruited Arab donors. The cheek swab for recruiting donors is an easy and efficient method. *(Dr. Amal Bishara)*

“If COVID19 has taught anything regarding transplant logistics, a large AUSTRALIAN registry of donors is crucial to ensure life saving stem cell transplants can continue during the anticipated period of reduced international travel.”

“This is a very cost effective and important program to continue as finding a donor for ethnic non white Australian is next to impossible currently.”

“My nephew had AML and a bone marrow transplant last year. He was matched with an overseas donor in the USA as an Australian match could not be found. At the time of his diagnosis there were many family members and friends who were keen to become bone marrow donors. The Red Cross process was complicated and not user friendly and consequently no one signed up at the time. When the Strength to Give swab process started they all signed up because it was so easy and it was in a format they could all access and understand. As a family we started Australian Marrow Match to help promote Strength to Give and to increase the number of donors on the registry.”

(Founder of Australian Marrow Match)



"I have a friend who has only just found a match on the registry after 3 years, overseas. The ease of signing up with a simple cheek swab, as available overseas may have saved her life. "

"The science is there - but we need the funding to be able to use it to save more lives. My brother in his 30s has AML leukaemia and I am his only sibling. I wasn't a match for him, and he is still waiting for a transplant. We need more people to register so that we can find matches for people like my brother, and the best way to do that is to make it as quick, easy and non-invasive as possible, like by a cheek swab." *(Family member/friend)*

"Having the Strength to Give cheek swab program available means that I can ask my family, friends and colleagues to register as a donor, and that they are more likely to do so because it's a non-invasive, quick and easy process. *(Family member/friend)*

"The target age group for stem cell donors is 18-30yo males, please make convenient and easy for this age group to join as they are not always the proactive or motivated to attend Lifeblood."

"Strength to Give provides a legitimate and tangible sense of hope and a realistic chance that a donor may be found. Without the cheek swab program and the online method of distribution to the target population, we would have zero chance of increasing the registry in a way that is applicable for us, it would be devastating." *(A family member or friend of a patient/ex-patient)*

"It must continue because it saves lives. It's a no brainer really!" *(A patient/ex-patient)*

"Australia needs to catch up with the rest of the world and register more donors. The government needs to fund this program. It is an essential service. Absolutely essential" *(Team Kai)*

"It means everything. We fought and struggled to get people to register. We have a Facebook page Team Kai with over 6,000 people. So many people commented about not liking blood tests. It put them off. So many more would have joined if cheek swabs were available. A large proportion of our Facebook group community are from the UK. It was very clear how much more effective and efficient registering people was in the UK as opposed to Australia. Children's (and adults) lives depend on people joining the registry."



Quotes of people's experiences completing a cheek swab

96% of survey respondents agreed that it was very easy to complete their cheek swab

"The cheek swab literally took 10mins start to finish. Signed up online, package delivered, swab & paperwork done, swab returned - done!! Matching donors to recipients will be so much easier." *(Someone who completed a cheek swab)*

"The cheek swab was such an easy process to get much needed data. The more people on the registry, the more lives saved, it's that simple" *(Someone who completed a cheek swab)*

"This is such a great, simple yet very efficient way to match people and save lives! It was very easy & convenient. Everyone should do it!" *(Someone who completed a cheek swab)*

"I have done a cheek swab to join the German registry and also the blood test to join the Australian. The cheek swab was much easier." *(Someone who completed a cheek swab)*

"It is incredibly easy, quick and convenient. It really allowed me to find what small time I had to complete it and send it off."

"It will literally save lives!! Our donor matches should be on our licence like organ donors" *(Someone who completed a cheek swab)*

Quotes of people wanting to do cheek swab drives or ran drives in the past

"When we were searching for a match for my son (Kai) we had drives both in Australia and the UK. We had 3 times as many people join the registry in the UK where they had swabs. It is simpler, faster and immediate. The blood tests often put people off joining the registry."

"If more funding was provided to allow for swabs, I am wanting to organise an awareness program and swab collection at my office. We have 600 employees, of which half might be eligible to join." *(Patient)*

"As a person going through this over the last 4 and a half years, the ease at which people can sign up, is something that I looked forward to. Having organised Red Cross drives, it's a lot more work to arrange a time where people



can attend to donate. Swabs being sent to a person's home saves time which is a huge commodity in our fast-paced society" *(Patient)*

"I have assisted a number of people to complete their swab kits and it has been so easy. In Northern Australia when Dengue Fever outbreaks often impact on the ability to donate whole blood for months at a time - cheek swabs can continue thereby ensuring we grow our pool of potential donors even when blood donor recruitment is somewhat difficult." *(Family member or friend of a patient/ex-patient)*

"Cheek swabs are a much easier more convenient way to get people onto the registry. In my experience, I was able to get 60 football players onto the registry due to the convenience of being able to bring the cheek swab to them. I had no such luck with the blood test prior as people are hesitant when they find out it is invasive testing." *(Family member or friend of a patient/ex-patient)*

"We have run multiple drives with ease using the swab kits and registered hundreds of people.. Lifeblood Red Cross are not set up for drives and there are major constraints *(Family member or friend of a patient/ex-patient)*

"To be honest I didn't know about cheek swabs until a friends son was diagnosed with leukemia, extensive drives were organised to get people on the registry." *(A family member or friend of a patient/ex-patient)*

"My partner has organised a number of bone marrow drives (using blood samples) and put a hell of all of hours into it. Swabbing would make the entire process way more simple." *(A family member or friend of a patient/ex-patient)*

"When my friend was diagnosed at 20, the swab program was not up. We were holding massive blood drives and it was exhaustive getting people to agree. The Swabs got the same amount of people involved with half the effort and half the time. DO NOT STOP THE SWABS YOU ARE DELAYING OR PREVENTING SOMEONES CHANCE TO SURVIVE."

"We are a minority ethnic group searching for a donor from a specific ethnic background. We rely on live donor drives at a culturally convenient time (ie at cultural events). Blood test donor drives are simply not possible for our desired population. We also have donors in rural/regional areas who simply can't attend Lifeblood for blood test but can very easily order a swab kit to their home and post back."

"I helped run my own drive and everyone commented on how simple it was!" *(Patient/ex-patient)*

"I haven't personally completed a cheek swab, but have been involved in developing group swab techniques which, with some further refinement, have the potential to be efficiently rolled out in a variety of situations, particularly



through sporting clubs and social organisations. Completing a cheek swab is quick and convenient and with modest organisation can be undertaken at a group level to increase donations.” *(President of the Geelong Cricket Association)*



Quotes from patients and their loved ones

"I feel that it is vitally important to explore every possible donor option available to help patients." *(Patient/ex-patient)*

"My daughter had a blood cancer and passed away in January. She was searching the registry worldwide and never found a match in over 6 years. This program needs to continue, far more people join up therefore a higher chance of finding a match" *(Family member or friend of patient/ex-patient)*

"As a patient who needs a Stem Cell transplant to fully recover, having a quick and easy way for people to join the registry will greatly increase my and many other people's chances of living a long and meaningful life." *(Patient)*

"I need an allo transplant, I do not have a match. Very soon I will have to go through a riskier transplant- haplo. Please please we need these cheek swabs in Australia. A special friend of mine had to go through a haplo transplant as she too did not have a match, she did not make it, leaving behind two young children" *(Patient)*

"If more people were on the registry my 45 year old friend and many others would have had a greater chance of finding a complete match. Tragically she passed away as all other options were exhausted and a half match transplant failed, consequently ending her life" *(Family member or friend of a patient/ex-patient)*

"Maybe my sister in law, who never found a donor and who died in January from a failed transplant, would still be alive if more people could have easy access to testing. She was a very big loss to her family, children but also Australia. She was a very successful forensic pathologist, and with her passing, Australia lost an asset." *(Family member or friend of a patient/ex-patient)*

"They are the FUTURE of bone marrow donations and are paving the way by offering hope to the hopeless and life to people who are told they don't fit the mould. We NEED them and I would implore the government to recognize that their efforts and work is groundbreaking, necessary to save lives which would otherwise be lost and above all valued by so many in the field and community. So long as blood cancer exists, we need Ur the Cure right there beside us, funded and ready to enlist community members to save lives." *(Family member of a patient/ex-patient)*

"(Holding live drives using cheek swabs) provides patients and families who are struggling to find a donor with a way to have some control and empowerment over their situation and take action." *(Family member or friend of a patient/ex-patient)*

"When the search was being undertaken for my husband and we knew that his siblings weren't a match, there was



a profound sense of powerlessness. We could see patients and families in other countries able to hold live drives but all we could do was encourage eligible people to donate blood and join the register at the same time.”

(Family member or friend of a patient/ex-patient)

“Cheek swabs saved my young daughter's life. It MUST remain.” *(Family member or friend of a patient/ex-patient)*

“My husband didn’t have a matched donor on the international registry so nearly didn’t receive his life-saving transplant. Fortunately, his sister was a 50% match and was able to be his donor as they had the same genetic material. His type of transplant was incredibly brutal but we had no choice. Otherwise, he’d be dead now. Plain & simple. We need as many people as we can on the registry so people have access to treatment if they need it”

(Family member or friend of a patient/ex-patient)

“I feel so terrible for those who are needing transplants at this very moment and can’t have access to their donors due to Covid-19. It’s heartbreaking.” *(Family member or friend of a patient/ex-patient)*

“When my friend was diagnosed at the age of 20, it was an absolutely horrible feeling, almost a year later and it still makes me upset. I would do absolutely anything to help him and his family try and find a match. To begin with, the blood tests were the only thing available. The drive that was held was a great success as all of his family and friends would do anything to help however after that, it got a bit harder. Friends of friends are not as willing to go and get a blood test for someone they don’t know as majority of people do not like needles or blood tests. As soon as the mouth swabs became an option, it got so much easier for people to agree to being tested as it was simple! Without this program, we would not have been able to spread as much awareness. It gave my friend so much hope every time a new person registered and I truly believe that gave him the strength to beat cancer.”

(Family member or friend of a patient/ex-patient)

“We were lucky that our German donor worked well but flight delays held it up by 24 hours. If we have another pandemic situation as we do now his will our loved ones get this life saving treatment if there are no local options.”

(Family member or friend of a patient/ex-patient)

“My brother has blood cancer (multiple myeloma). He has been given 3 years to live if he doesn't find a match. My brother is 41, with a wife and two young children. It is shocking that we are considering stopping the funding of such a simple, critical mechanism that could save his, and hundreds of thousands of other people living with blood cancer.” *(Founder 10,000 Donors Down Under)*

“After my sister relapsed twice from Leukaemia I donated stem cells through our hospital. Unfortunately Leukaemia still got the better of her but my stem cells were able to give her two precious more years with us - two



years she would not have had. After her passing I wanted to go on registry to help another but even though I was fit and healthy, I was denied because (as a man), I was in a long term monogamous relationship with another man. This cheek swab allowed me to register and, once again, be available to help someone in need.” *(Someone who completed a cheek swab)*

“My boyfriend recently went through a unrelated donor match bone marrow transplant and I couldn't even thank that mystery donor enough and I hope one day I can repay the favour and help someone else!”
(Family member or friend of a patient/ex-patient)”

“My daughter was lucky enough to find a good match on the registry, but she knew people who could not find a match, one of who has died. *(A family member or friend of a patient/ex-patient)*

“Strength to Give could save my life & my 3 children would have a mother” *(A patient/ex-patient)*

“We lost our son because we couldn't find a suitable donor. Any one person who joins the registry increases the chances for someone else to live” *(A family member or friend of a patient/ex-patient)*

“My First Grand Child died for there could not be found a matching donor. Therefore it is vital to swab as many people as possible to save lives.” *(A family member or friend of a patient/ex-patient)*

“I have lost friends who needed a match to be found, but one wasn't found in time to save them. Taking away the hope of, not only the patient, but their loved ones, is cruel. There needs to be as many ways to register as possible.”

“My son Kai has two bone marrow transplants and passed away at 3 years old. He would not have survived as long as he did without a bone marrow match. I am a committee member of the kids Cancer support group. I see so many heartbreaking cases of children who are unable to find a match. Their lives literally depend on it. Now more than ever is vital to register as many Australians as possible. Donor cells are unable to come from overseas, their chances are limited even further. Cheek swabs are without a doubt the fastest and most effective way to register donors. Families are desperate.”

“It means hope. It means that my chances of finding a match are significantly increased. It makes me wonder why this isn't standard when it is in so many other parts of the world! I would feel disappointed and let down by the people who are supposed to be caring for me if it was discontinued. It clearly drives people to get on the registry



due to ease and access. It clearly saves lives. The Australian government would be blind to not see this.”

(Patient/ex-patient)

“My 40 year old brother in law with a very aggressive AML had his life saved within 3 months of diagnosis by an anonymous 22yo male donor on the ABDMR - thank goodness this young man had registered as my B-in-Law was not a match to any of his 4 sisters, and he was very lucky to be of Caucasian heritage.” *(A family member or friend of a patient/ex-patient)*

“My partner has been diagnosed with Hodgkins lymphoma and she need a donor for an stem cell transplant - unfortunately we can’t find anyone in Australia that is 100% match for her - we found an overseas donor however with the Coronavirus we cant access to the donor either. We need to keep this program in place as we need to increase the number of donors so more people can have access to a potentially life saving option.”

“I have a friend, who was diagnosed with blood cancer at 20 years old! He is in remission but he is not safe. There is no match as of yet. This list NEEDS to expand rapidly not steadily.”

“Every minute of every day there are people desperate waiting for a match to be found for themselves or a loved one, who is fighting for their life. If cheek swabs stop you are taking away that last chance and hope for another chance at life. I don’t know how anyone with a conscience could even consider that.”

“It is life and death for me and others going through blood cancer and to remove the swab programme is not giving a fair chance to those fighting blood cancer with everything they have.”

“I have a son who had blood cancer as a child. At that time there was only blood tests available. The cheek swab program is so important to recruit more donors for those in need. Strength to Give do an amazing job.”

(A family member or friend of a patient/ex-patient)

“If there had been more people on the bone marrow registry, my partner may have found a better match and could still be with me.” *(Founder of the TLR Foundation)*

Anecdotal Evidence – Other Quotes

“When you have a patient in front of you whom you cannot match with a blood donor, it's heart-breaking. They can literally die waiting for a donor. Any program that increases the Australian bone marrow donor pool is worth supporting and funding.” *(Health professional)*

“There is a tragic lack of knowledge and awareness about the stem cell registry in Australia. Through our campaign (10000donors.com.au) and the donor drives we have been running, the consistent message is the Australian public want to help, however had not knowledge or information about the stem cell registry. Swab kit donor drives provide an ideal mechanism to educate the public and provide a simple way to join the registry.”

(Tim McCleave, 10,000 Donors)

“As a country as wealthy as ours not having a community approach to bone marrow transplant is embarrassing. If more people knew that for some patients this is the only way to survive then I think we could get this done.”

(A family member or friend of a patient/ex-patient)

“We at the World Marrow Donor Association (WMDA) believe the cheek swabs need to remain in Australia. It is a non-invasive and fast way of registering donors. It is important for Australia to increase the number of donors available for patients in need! Being reliant on overseas donors is possible but less desirable because of for instance cost and transport risks. It is highly recommended to give potential donors as many options as possible to be able to join the registry.” *(Monique Jöris – World Marrow Donor Association)*

“As a BMT nurse working in the current climate I cannot express how strongly I agree that federal government should fund the continuation of this essential program. With mostly overseas donors normally, this pandemic has had significant cost and personal impacts on patients and staff. Having a strong national registry would significantly reduce the overall BMT cost during transplant and post! We need to do better!”

“Australia's current donor pool for life saving stem cell transplants does not meet the needs of Australian patients (with over 80% of donors needing to be sourced from overseas) and it is clear we need more suitable donors and more diversity in our donor pool. That is why we are supporting efforts to expand the local donor pool and why we are one of the community partners for the Strength to Give program” *(CEO of the Leukaemia Foundation)*

Appendix

Appendix A: Anecdotal evidence from the 2017 survey of people's experiences when trying to join the ABMDR

The survey asked a number of questions asking people what they believe needs to change to make it easier for people to join the ABMDR to improve the donor pool. A number of questions were also directed at people's experiences with Lifeblood such as, "Have you ever donated blood"? "When you donated blood were you offered information or asked to join the ABMDR"? "Have you ever been rejected to join the ABMDR because you lived in the UK during the mad cow period?" and more. People were asked to identify their age and cultural background to also determine who would have been ideal candidates to join.

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

"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

"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