

**Submission  
No 44**

**INQUIRY INTO INCREASING THE NUMBER OF REGISTERED ORGAN  
AND TISSUE DONORS**

**Organisation:** Ur the Cure  
**Date Received:** 29 August 2023



**UR THE CURE**

Education – Awareness – More lifesaving matches

29 August 2023

Parliament of Victoria

Legislative Assembly Legal and Social Issues Committee

Parliament House, Spring Street

EAST MELBOURNE VIC 3022

Via email: [registerddonorsinquiry@parliament.vic.gov.au](mailto:registerddonorsinquiry@parliament.vic.gov.au)

## **Victorian Parliamentary Inquiry into increasing the number of registered organ and tissue donors**

### **About UR The Cure**

#### Education, awareness and donor recruitment

UR the Cure is a registered charity with the ACNC (Australian Charities and Not For Profits Commission) and is run completely by volunteers. Based in Victoria, it was founded in 2015 by Pamela Bousejean after her diagnosis of Hodgkins Lymphoma (a type of blood cancer) and her personal experience in struggling to find a stem cell match to cure her cancer due to her Lebanese heritage. UR the Cure is a partner of the Australian Bone Marrow Donor Registry (ABMDR) who run the "Strength to Give" cheek swab program.

UR the Cure helps blood cancer patients find their lifesaving stem cell match. Our work focuses on education and raising awareness about blood stem cell donation and giving people the opportunity to join the blood stem cell registry (Australian Bone Marrow Donor Registry - ABMDR). Patients with a blood cancer or other type of blood disorder rely on having a stem cell transplant (also known as a bone marrow transplant) as their chance for a cure. This means they need to find a stem cell match. People can voluntarily join the donor registry so doctors can search for lifesaving stem cell matches for their patients. Patients with a culturally diverse or indigenous background struggle to find their match as there are not enough people with these backgrounds registered as potential donors.

Over 80% of Australian patients now rely on receiving their stem cell match from overseas. To find the best matches, our work particularly focuses on young males aged 18 to 35 of all backgrounds and those with a culturally diverse or indigenous background to join the donor registry.

#### Advocacy

UR the Cure also advocates on behalf of patients and families to improve the donor recruitment systems in Australia. Essentially the underlying problem in Australia is the difficulty and limitations on people being able to join the donor registry. The solution we have been advocating for is the implementation of cheek swab testing (buccal swabs). We have been advocating for the implementation of cheek swabs since 2017. Some of the activities we have undertaken include:

- A written submission to the government-funded independent review of the Australian Bone Marrow Transplant Sector, highlighting 6 key recommendations to improve donor recruitment strategies, one of which was to introduce cheek swab testing. A survey commissioned by UR the Cure received over 500 responses, providing data, direct experiences, insights and opinions to inform the submission recommendations (2017)
- A campaign which encouraged supporters to write to their local MP's regarding funding for cheek swab testing in the lead up to the election (2019)
- Conducted a "Save Our Swabs" campaign and ran a petition and survey, with almost 300 people submitting a response with detailed commentary on their experiences joining the donor registry through blood donation versus cheek swabs (2020)
- Involved in the feedback panel for the Leukaemia Foundation's National Strategic Action plan and encouraged the Leukaemia Foundation to advocate for cheek swab testing to help achieve their strategic goals (2020)
- Feedback provided to the INCA Consulting group and ABMDR evaluation report regarding the Strength to Give pilot program for cheek swab donor recruitment (2020)
- Video developed for World Marrow Donor Day urging the world community to support our campaign to introduce cheek swab testing into Australia, shared through the World Marrow Donor Association networks and media (2021)
- Involved in various media stories to shed a spotlight on the issues around Australia's donor pool (2015 to present)
- Social media campaign and education regarding the importance and need for cheek swab testing in Australia (2022)
- UR the Cure's statement of support published on the Australian Bone Marrow Donor Registry website as a peak patient organisation, for the introduction of cheek swab testing (2022)
- In conjunction with @Biffrunner, "The 20-50" campaign launched to raise awareness on the need for cheek swab testing, encouraging the public to sign the petition and write letters to the Federal and State Health Ministers with letter templates provided by UR the Cure made available to download on our website. We also engaged with a number of different organisations calling for their support (2022)
- "The 21st-50" campaign launched; with over 7,000 signatures reached on the petition, UR the Cure coordinated volunteers around Australia to hand-deliver the petition to the State and Federal Health Ministers which sparked a series of meetings with various Health Ministers and politicians including with the Assistant Federal Health Minister Ged Kearney, NSW State Health Minister Brad Hazzard, QLD State Assistant Health Minister Julianne Gilbert and staff from Health Minister D'Aths office and more
- Worked with MP Robbie Katter's office who helped advocate for the introduction of cheek swab testing into Australia; assisting with feedback for media releases and government correspondence and providing information (2022)
- Meeting with the Deputy Prime Minister Richard Marles about the need for governments to approve the use of funds for cheek swab testing (2022)
- Presented to the government's Clinical Advisory Group on the need to introduce cheek swab testing and other specific matters regarding how the cheek swab program should be rolled out (2022)
- Various correspondence and letters written and received by the Federal Health Minister and State Health Ministers over many years

## **The patients and families we represent**

Our submission is not filled with statistics and facts; we fully support the ABMDR's submission which contains all the necessary statistics, facts and information on why and how we need to grow our local donor pool. Our submission is about the patients and families who are impacted by the issue, the humanitarian side; the reason our health services exist to serve.

As seen above, UR the Cure has done a lot of work in this space and the government have been well aware of the issue for a very long time. Through surveys we have conducted and through our networking, we represent all the patients and families who have waited far too long for governments to take action.

We cannot wait for endless reviews. We cannot wait for investigations around TGA approvals which we know have caused delays in the past, despite the fact that TGA approval is not required. We cannot wait to undertake more pilot programs. We cannot wait until an Australian laboratory is established. We need action now.

Cheek swabs are the gold standard for recruitment, they are the reason we rely on over 80% of stem cell donations to come from overseas in the first place. Patients and families do not understand why cheek swabs can be so routine and uncontroversial elsewhere for so long but not the case here in Australia. The sentiment amongst the patient community is now turning to absolute frustration and anger over government's inaction, and also despair as though the government do not care enough about their lives. It is reaching boiling point, blood cancer patients have been neglected for too long now, long before the Covid-19 pandemic; the pandemic simply exacerbated the situation.

## **What UR the Cure and the entire patient community are asking for**

- Quick implementation of the Strength to Give cheek swab program. We just need to get started! There's such little awareness in Australia about stem cell donation so we need to raise the public profile first. And by starting it gives the ABMDR and organisations like UR the Cure the opportunity to work with different groups for further learnings so we can better target the right demographic
- Release the **full \$12.8 million of funds** to the Australian Bone Marrow Donor Registry, the ABMDR need to be the core organisation responsible for donor recruitment. We also have concerns that this amount of money can be held for so long in a bank account unused, it's unethical
- Use the already established overseas laboratories to test the donor registration samples; they produce more accurate results with a faster turnaround time and are more cost effective in comparison to Australian labs. In the meantime we can undertake preparations to get an Australian lab established. If patients are truly at the heart of decision making then this is the best approach. Otherwise it causes more delays and does not use the funds in the most effective way to improve our donor pool efficiently

## **Patients and families have been severely impacted**

Patients feel unsupported and left completely on their own to fend for themselves during the hardest time of their life. The moment a patient is told they need to find a stem cell match is when the real anxiety and stress begins, and they realise that there is basically no support for their search. They often reach out to overseas organisations to gain any sort of support. Below are just some of the stories we have come across, they are just the tip of the iceberg.

- Vanessa was the first adult to receive a cord blood stem cell transplant in Australia over 25 years ago. She was unable to find a match because of her Chinese heritage. Nothing has

changed. Ethnically diverse patients struggled 25 years ago and 25 years later they're in the same position. People like Vanessa wonder whether things would be different if it was "white Australians" impacted

- Matt was a young father of 2 girls who sadly passed away due to complications from delays in receiving stem cells from overseas
- Melissa was a single Mum of 2 young children when she passed away in her 40's due to not being able to find a stem cell match
- Javeria lost her 15 month old son because of difficulties in finding his match due to his Pakistani background
- Louise lost her 4 year old son due to difficulties in finding his match
- Kruz is a 4 year old boy currently searching for his stem cell match



*Matt a father of 2 young girls passed away in 2021 due to complications from delays in receiving a stem cell transplant*



*Melissa, a young single Mum of 2 passed away in 2020*



*Zakariya passed away at 15 months old due to no match in 2014.*



*Jack passed away at 4 years old due to no match in 2021.*

How many more young children and people have to die before the government take action? We know that we couldn't have guaranteed that these people would've found a match had we introduced cheek swabs years ago and created a better donor pool, but can the government look at these people in the eye, these mothers and fathers who have lost children and say they did enough?<sup>4</sup>

The answer is a strong no. There's too much talk and not enough action. Patients need to be at the heart of all decisions.

### **UR the Cure as a donor recruitment organisation**

The reason UR the Cure started was to increase the number and diversity of Australia's donor pool. We have realised that it is impossible to achieve this goal without cheek swab testing. Government restrictions on the ABMDR and its flow on effects is limiting the availability for a reliable source of cheek swabs to achieve our charity goals. We tried to run donor recruitment within Australia's existing methods of blood donation and for many reasons, barriers, limitations and challenges; we have realised it is in fact an impossible task.

We partnered with the ABMDR during the Strength to Give cheek swab pilot program. Our work is completely dependent on the reliable source of cheek swabs and with the swabs, we can support the ABMDR to help achieve our common goals.

### No assurances for longevity of the donor recruitment program and its stop/start nature

UR the Cure has never had any assurances on the availability of cheek swabs beyond 12 months which makes it difficult to operate on many levels. We need at least 3 years of an open program to do the work properly; engage with other organisations and people, establish ongoing relationships and donor recruitment programs and maintain positive momentum to keep everyone motivated and committed rather than constant stop/starts.

For example it can take 6 to 12 months to establish an ongoing relationship with the ethnically diverse groups that we engage with. Note that our goals are not to run one off recruitment drives, we are looking at implementing a systemic ongoing recruitment program with these groups to capture eligible donors year on year, particularly as people turn 18 years old and therefore eligible to join. The dribs and drabs of funding trickling through is not enough. The governments thus far have still not released any of the funds despite promises made earlier this year. **Governments need to release the full \$12.8 million of funds upfront.** Releasing money in small amounts is counterproductive and eats into this vital pool of funds, it is an inefficient use of funds.

We understand that the government are now looking at releasing a small amount of funds to go towards donor recruitment until June 2024. This is again too short term. It will act like another pilot program as they will no doubt pause the program in June next year to undertake more reviews. We don't need more pilot programs to prove what we already know. The previous pilot has already proved its success, the rest of the world are using cheek swabs as the gold standard for recruitment.

The slow stop start nature of cheek swab recruitment also means we don't have enough time to establish meaningful ongoing relationships with other groups and organisations. Often key contact people within the groups have moved on by the time we re-approach and then we have to start the process all over again, it breaks momentum not to mention trust and credibility.

### More information regarding how cheek swabs need to be implemented to help us achieve our goals

- They must be offered in a flexible way (ie – ordered online to target young donors) and have the ability to use within the community to better target the ethnically diverse groups and males
- Having cheek swabs available in the community are a support mechanism for patients and their families which also has flow on benefits to recruitment and targeting the right groups (ie – patient-led donor drives gives you access and valuable insights into ethnically diverse groups)

- Having clear visibility on reporting to measure outcomes will be crucial for any partner organisations involved (regarding how many people have joined the donor registry as a result of their activities). Blood donation registrations prevents this. Cheek swabs allows clear measurement of our donor recruitment programs, this is important as partner organisations are needed to help achieve the target numbers and to target the right demographic

#### A note on the use of the overseas laboratory versus an Australian laboratory to test samples

There is growing concern that government decisions to establish an Australian lab(s) rather than using the already established overseas labs will cause more delays and impact patient outcomes.

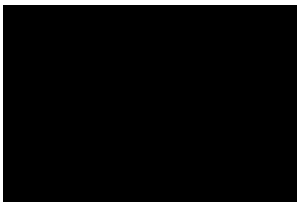
During the pilot program we experienced such delays when the ABMDR started using local labs to test the samples. It used up a lot of administration time for us as we responded to concerns from donors who had completed their swabs and many weeks/months later still hadn't received confirmation that their sample had been added to the registry. We need to create trust with potential donors who are registering and it's an important part of the entire donor experience.

We are also aware that overseas labs produce more accurate results with a faster turnaround time and are more cost effective. Most registries around the world use these same labs to do their testing. If the government insist they want to set up a lab in Australia then they can do so whilst in the meantime we send our samples overseas for testing rather than causing more delays. It's also not the most efficient use of the funds if we are truly looking at improving donor recruitment, we need to use the funds to achieve a big impact and get our donor pool up to scratch as fast as possible. If improving our donor pool is truly the goal of the government then using the overseas labs at least initially until our labs are ready is the best approach.

We thank you for the opportunity to provide a submission to this inquiry. As a Victorian based charity, we hope that Victoria can take the lead for the changes we so desperately need by releasing the \$12.8 million in funds to support and save the lives of all Australians.

Please don't hesitate to contact me on the details below for any further information.

Kind regards,



Pamela Bousejean

UR the Cure Founder

