



## UR THE CURE

Education – Awareness – More lifesaving matches

*Improving ethnic diversity on the Australian and worldwide stem cell registries*

10<sup>th</sup> February 2023

The Hon. Mark Butler

Minister For Health and Aged Care

By email: Minister.Butler@health.gov.au

Dear Minister Butler,

I am writing today as a follow up from our meetings last year regarding approving the use of existing funds for cheek swab (buccal swab) testing to improve Australia's stem cell donor pool. I'd like to thank everyone for taking the time to meet and/or write to me these past 12 months. As I was writing this email earlier this week we heard some very promising news and I would like to extend a very big thank you for your commitment to get Australia up to speed with the rest of the world and introduce cheek swabs. It's a moment that we as the patient community have been waiting for a very long time and there are lots of people celebrating this exciting news!

It's safe to say that everyone is across the issue now at a State and Federal level and we've also had hundreds of supporters write to their local MP's about this issue, and I think everyone agrees we have a problem in Australia that needs to be fixed as soon as possible. As this matter requires a collective decision between both State and Federal governments, I wish to provide a summary of all our meetings from last year. I'm aware this letter is lengthy but I really appreciate your time having a read through as I believe it's important that everyone is on the same page and across what we are advocating for so we can keep moving forward towards the solution. If you can provide a comment on the "follow up action" within your section that would be great, I want to keep this top of mind for everyone involved so we can implement the solution as soon as possible. Our Advisory Group presentation summary below also outlines what we believe the solution needs to look like.

After our meetings we had mixed support amongst the States and are now desperately seeking everyone's support to get this happening, and it seems now that we have full support at the Federal level. Please be aware that we have also sent this letter to all other State and Territory Health Ministers, the Assistant and Federal Health Ministers and the Deputy Prime Minister of Australia who we also met with last year. We have thousands of supporters whom we represent who are all eagerly waiting on an outcome, our views and what we are asking for represent all our supporters, gathered from years of networking and conducting surveys with over 800 respondents.

### **ADVISORY GROUP PRESENTATION AND SOLUTION SUMMARY**

- Pamela, founder of UR the Cure presented to the Advisory Group on 2<sup>nd</sup> December 2022
- Some of the key points made in the presentation:
  - o Importance of acting fast and the government to implement the solution fast

- Use of buccal swabs to be used for the majority of donor recruitment
- 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)
- We need to recruit 100,000 to 200,000 donors in the next 5 years
- We strongly support the Australian Bone Marrow Donor Registry (ABMDR) proposal of using existing funds from the cord blood stem cell sector to implement a 5 year recruitment program
- The ABMDR need to be consulted with and included in the conversations...as well as others with experience in donor recruitment (not just clinicians, TGA reps etc who are only really involved once the patient finds a match) and the ethnically diverse communities need to be consulted if discussions are being had on how to best target these groups
- We believe the ABMDR need to be the core organisation responsible for donor recruitment which can be complimented by Red Cross Lifeblood and partnerships with other organisations (UR the Cure survey results available on request regarding people’s experiences joining through Lifeblood which has formed the basis of why we believe it needs to be the ABMDR). Essentially we believe implementing the changes within Lifeblood will take too long, cause further delays and not be as effective compared to the ABMDR, particularly since Strength to Give was a success and is ready to go!
- 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). Including partner organisations will be needed to achieve the high target numbers
- 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 then refine targeting once we have started

## STATE GOVERNMENT MEETING SUMMARY

### **Queensland Meeting - 12<sup>th</sup> August 2022**

- We met with Assistant Health Minister Julieanne Gilbert and a number of others from government health departments and staff from Minister D’Ath’s office
- Qld committed to improving the donor pool and to work with other governments to achieve this goal
- Qld did not agree to write a letter of support to the Federal Health Minister but committed to investigating the matter more to see if they felt comfortable writing a letter of support
- We have also been working in the backgrounds with MP Robbie Katter who has been helping to advocate for the cause
- We received a letter dated 12/09/2022 advising to get in contact with the Advisory Group which we since presented to (see above)
- We also received a letter dated 31/03/2022 stating that Queensland patients are not subject to significant wait times. We are advocating for all Australians no matter where they live and require the support of all States and Federal governments. This has caught media attention in the past year with a number of stories published, most recently on the 23/1/2023 with the Adelaide Advertiser and the Townsville Bulletin and Liam O’Brien’s recent public campaign, unfortunately these desperate patient public campaigns are not uncommon and happen time and time again

- ***Follow up action: Can Queensland confirm that someone has looked further into the matter and does the government now feel comfortable in supporting the changes that the Federal Health Minister wants to pursue?***

#### **Northern Territory Meeting – 17<sup>th</sup> August 2022**

- Met with Deirdre Logie Deputy Director, National Partnerships and National Critical Care and Trauma Response Centre
- NT committed to writing a letter of support to the Federal Health Minister and acknowledged that this is an issue that impacts indigenous Australians and their difficulties in finding a stem cell match
- ***Follow up action: Can NT confirm that this letter of support was sent and are they willing to continue to support the changes the Federal Health Minister wants to pursue?***

#### **New South Wales Meeting – 28<sup>th</sup> September 2022**

- Met with Health Minister Brad Hazzard
- NSW were very forthcoming with their support and Minister Hazzard agreed to personally hand deliver letters of support to his State Counterparts at their next meeting in Adelaide
- NSW have also proactively provided us with a letter signed by Minister Hazzard confirming he sent the letters of support to his State Counterparts and that a letter of support was sent to the Federal Health Minister
- ***Follow up action: Are NSW happy to continue their support for the changes the Federal Health Minister wants to pursue?***

#### **Victoria**

- Meeting request sent by our volunteer Matthew Thompson on 18/07/2022
- Meeting request not granted, a letter was received on 27/09/2022 stating that the government are committed to improving the donor pool and that a thorough assessment of the Strength to Give cheek swab program needs to take place
- ***Follow up action: Is Victoria comfortable in supporting the changes that the Federal Health Minister wants to pursue?***

#### **South Australia**

- Meeting request sent to Health Minister Picton 30/06/2022
- UR the Cure followed up on 07/07/2022
- No response to this request received
- Other correspondence has been sent and received in the past about the matter including a letter from the 22/2/2022 stating that the government are committed to improving the donor pool and that a thorough assessment of the Strength to Give cheek swab program needs to take place
- ***Follow up action: Is South Australia comfortable in supporting the changes that the Federal Health Minister wants to pursue?***

#### **Western Australia**

- Meeting request sent to Health Minister Sanderson 28/06/2022
- UR the Cure followed up on 07/07/2022
- No response to this request received

- Other correspondence has been sent and received in the past about the matter including a letter from the 30/05/2022 stating that the government are committed to improving the donor pool and that a thorough assessment of the Strength to Give cheek swab program needs to take place
- ***Follow up action: Is Western Australia comfortable in supporting the changes that the Federal Health Minister wants to pursue?***

#### Tasmania

- No meeting request sent, other correspondence has been sent and received in the past about the matter including a letter from the 25/05/2022 stating that the government are committed to improving the donor pool and that a thorough assessment of the Strength to Give cheek swab program needs to take place
- ***Follow up action: Is Tasmania comfortable in supporting the changes that the Federal Health Minister wants to pursue?***

#### ACT

- No meeting request sent, other correspondence has been sent and received in the past about the matter from a supporter, Louise Stevens from the Forever 4 Foundation (she sadly lost her 4 year old son whilst waiting for a match), she received a letter stating that the government are committed to improving the donor pool and that a thorough assessment of the Strength to Give cheek swab program needs to take place
- ***Follow up action: Is the ACT comfortable in supporting the changes that the Federal Health Minister wants to pursue?***

### FEDERAL GOVERNMENT MEETING SUMMARY

#### Federal Assistant Health Minister Ged Kearney Meeting

- UR the Cure volunteer Matthew Thompson met with Federal Assistant Health Minister Ged Kearney on the 15/07/2022
- Minister Kearney expressed her support on the matter and expressed the need to garner State support
- Minister Kearney also advised us of the Advisory Group that has been set up to provide recommendations on donor recruitment
- ***Follow up action: UR the Cure will be in contact shortly for updates on the Advisory Group meeting outcomes and timeframes on when to expect the Advisory Group recommendations and actions***

#### Federal Health Minister

- Meeting request sent to Health Minister Butler on the 28/06/2022
- A meeting was initially offered with Minister Butler's advisor but not followed through after a number of attempts
- We received a letter response on 09/08/2022 stating that the Federal government are committed to improving the donor pool and that an Advisory Group has been set up. The letter also stated that Medicare and Aged Care are a priority
- ***Follow up action: We thank the Federal Health Minister for his strong statements of support made earlier this week. We strongly believe that although there are other government priorities, the fix to the stem cell donor pool is an easy one by simply continuing the Strength to Give program and doesn't require any more time for decisions to be made. Blood cancer patients have been waiting far too long for a solution with***

***previous government reviews and discussions spanning the last 10 or so years without any action. Implementing the changes is an “easy win” for the newly elected Labour government and won’t take long so the government can continue focusing on Medicare and Aged Care***

#### **Deputy Prime Minister Richard Marles meeting**

- Pamela, founder of UR the Cure met with Deputy PM Richard Marles on 12/12/2022
- The Deputy Prime Minister offered strong support and stated he would talk with and personally write to the Federal Health Minister about the matter
- ***No follow up action required, we thank the Deputy PM for all of his help and are so grateful for his support on this matter over the years***

If anyone wishes to discuss anything further with me I am always willing and able to meet at your convenience so please don't hesitate to get in touch.

Kind regards,



Pamela Bousejean

*UR the Cure Founder*

[info@urthecure.com.au](mailto:info@urthecure.com.au)

Ph: 0416 047 807

