

UR THE CURE

Education - Awareness - More lifesaving matches

23 February 2022

By email: The Australian State and Federal Health Ministers and Shadow Minister

Dear Ministers,

I have included all State and Federal Health Ministers in this communication as this matter requires a collective effort for a decision to be made.

Firstly, thank you to those who have responded thus far. It has been brought to my attention that another independent review is taking place of current and international best practice in HPC donor recruitment and retention. What is the name of this review and when is it scheduled to complete? What is the review hoping to achieve? And what are the timeframes for implementation of a solution to start saving the lives of Australian patients?

A number of reviews have already taken place over many years, including an independent review of the Strength to Give program by the Inca Consulting group in May 2020 which has been provided to governments.

We cannot keep running review upon review while Australians are dying waiting for their stem cell match.

Australian patients and their families have been waiting too long. This has been an issue in Australia for over 20 years now. The previous review took 4 years to complete. Page 15 of the Framework states the need in "improving the ability of the sector to meet the needs of the community in an equitable and timely manner". The current situation is not equitable or timely for patients.

Whilst I appreciate the reviews will inform a future approach to HPC donation and may require complete overhauls of the system for the better, it is a long-term approach and may take many years to implement. In the meantime, there is sufficient evidence that Strength to Give is a successful program. The very reason Australia imports over 85% of stem cell donations from overseas countries is because the cheek swab testing method was adopted overseas many years ago.

Strength to Give can be implemented almost overnight and can start saving the lives of Australians immediately. Whilst we wait for reviews to complete and decisions to be made, I urge the governments to collectively approve and make an amendment to the Australian Bone Marrow Donor Registry (ABMDR) contract, and allow the ABMDR to access the \$13 million dollars sitting in an existing bank account to conduct the Strength to Give program.

I also urge all governments to put the patients and their loved ones at the centre of all decision making. The bureaucracy of it all (for example which labs are awarded the work) should not cause further delays and can always be changed at a later date. We cannot continue hearing the heartbreaking stories of blood cancer patients in desperate need of a stem cell match, we have waited long enough. UR the Cure along with its thousands of supporters plan to continue pursuing this matter further at all levels.

Kind regards,

Pamela Bousejean UR the Cure Founder



UR the Cure Inc 2015 ABN 77 318 048 582

www.urthecure.com.au info@urthecure.com.au