

ORGAN AND TISSUE DONATION

On 13 February 2023 the Standing Committee on Public Administration resolved to establish an inquiry into organ and tissue donation in Western Australia. The Committee will inquire into and report on:

- a. the effectiveness of the current model for organ and tissue donation in Western Australia
- b. issues impacting organ and tissue donation rates in Western Australia
- c. opportunities to improve organ and tissue donation rates in Western Australia
- d. any other matters considered relevant by the Committee.

The following is a submission made by

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[Senior Advocate & Changemaker](#)

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My Story,

I would like to introduce myself to you ahead of my submission and of my pending visit to Perth for the World Transplant Games in April.

I am a forever grateful recipient and passionate advocate for Organ and Tissue Donation and Transplant Awareness. I pride myself on key stakeholder management, dealing in a professional manner and ensuring that I represent myself in an honest, transparent manner in all my advocacy dealings.

I give credit to those who have come before me and acknowledge when others do good things, amplifying their messages to as many influential people as I am able to deal with. My journey has brought me into contact with amazing people who agree that there is a lot more we can do as a society, to save lives by increasing awareness around organ and tissue donation and lifesaving transplants.

Politicians at a federal level, across multiple states and from all political persuasion have listened to my story and taken note of the need for an approach that covers Legislation, Communications and Education.

In just 12 months since waking from surgery, I have been involved in making some significant advancements across the transplant journey and across Australia.

On the last Friday in March 2021, I went reluctantly to the GP at the request of my beautiful wife. I presented on a Friday afternoon in not expecting to get an appointment on the same day, and was surprised when I was told a doctor would see me in just a few moments. Dr Soliman approached me from his consulting room and asked if I was Rob Manning, I said yest and started toward him. He looked at me and his first sentence was “you are a very sick man, why are you here?” I said “nice to meet you too.!” He further enquired as to why the fat belly and the yellow spot in my eye. “I probably eat too much, drink too much and don’t exercise enough!”

Long story short, when I called on Monday, to get the results of the barrage of tests he conducted on Friday he said he had to see me that day. In the afternoon of Monday 28th of March, I was admitted for a two week stint in Royal North Shore Hospital. More tests and more denial from my part that I was sick and I was let out to resume a normal life, interspersed with fortnightly visits to the Liver Clinic. On around the 3rd visit, I was advised by the Specialist, I had 12 end stage liver disease and an estimated 12 months to live without a transplant.

Fast forward just 6 months and my world had completely changed. From not feeling sick to a raft of test, counselling and consultations before spending 2 weeks in hospital for heart stents and other minor procedures. On 17 December, I left RPAH to spend perhaps my last Christmas with family and prepare for 2022, when hopefully before May or June, I would be ready for a transplant if a suitable donor could be found.

On Sunday 19 December, I awoke with lower back pain and some disorientation. I deteriorated quickly and by noon, I was naked and delirious when my wife returned from a brief trip to fuel the car for our return to Sydney. By 6pm that day I had suffered catastrophic liver and kidney failure and placed in an induced coma, which would last 14 days.

When I awoke from my coma, I discovered I had a new liver and a new lease on life³. Since then I have been advocating with unbridled passion from lived experience, harnessing the skills and experience I have acquired in over 30 years of management across government and private enterprise and it is something I will continue doing for the rest of my life. Rattling chains, shaking trees and sharing the knowledge and experience of others to convey important messages is what I do & it's achieving measurable results and getting things done.

Why I am making a submission

Since having everything do miraculously right after it had gone catastrophically wrong, my life was saved at the very end of 2021. When I woke from a two-week coma and lifesaving surgery, I became a committed advocate to ensure every Australian no matter where they live would receive the same opportunity as I received should they ever need it.

My Advocacy Journey started in January 2022, and I have worked to advance awareness for Organ and Tissue Donation passionately and enthusiastically. I have sought an understanding from the Authority's perspective and Transplant Australia to understand the donor registration drive and the recipient journeys.

As a recipient who is forever grateful, I sought to get the perspective with Donor Families Australia and understanding the issues they faced as brave donors of deceased organs. I have worked with ShareLife Australia and clinicians to understand the challenges that exist in hospitals. I have worked to bring together all parties across the landscape to improve the lives of Chronically Ill, Transplant Recipients, Donor Families, and everyone else involved in the Donor and Transplant Journey.

Reference links – Supporting information for all claims and initiatives are available at the following links, including articles, videos and community feedback and engagement.

www.transplantadvocacy.com <https://www.facebook.com/robmanningsydney>

<https://www.linkedin.com/in/robmanning/>

I would be willing to meet with the Inquiry to present in person.

My Advocacy Record

Western Australia

In my first 12 months of advocacy, I mark as my major achievements as:

Working with Minister Amber Jade Sanderson's office to have a letter sent to DonateLife, Donor Families Australia and Transplant Australia providing certainty to donor families to be able to celebrate and commemorate their loved ones without concern of prosecution under Section 34c of the HTTA Act. I also encouraged the creation of the Friends of Organ Donation group for this Parliament.

I worked with the Minister and Leader of the Opposition to initiate discussions to form the Friends of Organ Donation

The Western Australian Parliament has revised the Human Tissue and Transplant Act 1982 forty years after it was first introduced thanks to some amazingly diligent work by Health Minister Amber Jade Sanderson, Simon Towler, Intensive Care Specialist in WA and many others. The WA Government are also reviewing the important clause relating to Disclosure of Information, S34c (2) which will be amended in a future submission to Parliament but the ability for all Donor Families to Commemorate their loved ones was addressed in the letter that was sent to Donor Families, DonateLife & Transplant Australia in July 2022.

Most recently I have written to The Minister's advisor and Mr Pierre Yang in relation to the parliamentary enquiry into organ donation in WA., with submissions due by end of March.

South Australia

- * Introduction of Births, Deaths and Marriages Amendment to allow posthumous recognition of donors
- * Use of national legislation to exempt South Australian Families from prosecution under TAA Act

ACT

- * Amended legislation to allow families to celebrate their loved ones.
- * Addition of link to OTA National Register on Access Canberra web sites

NSW

In my home state of NSW, with the support of David Mehan, MP for The Entrance and Adam Crouch the member for Terrigal the Friends of Organ and Tissue Donation and Transplant Awareness was formed in Australia's oldest parliament. Working with Justin Clancy, MP for Albury and Tim James, MP for Willoughby more initiatives have been introduced into parliament that will make a difference. In his Speech to Parliament, Mr Clancy also acknowledged:-

"the wonderful work being done by the Australian Organ & Tissue Authority, Transplant Australia, DonateLife, Donor Families Australia, the Attorney General, the Minister for Health, the Minister for Customer Service and Digital Government, and advocates such as Robert Manning who help drive this important conversation."

- Formation of the NSW Parliamentary Friends of Organ and Tissue Donation and Transplant Awareness.
- Review of 2012 Plan to Increase Organ Donation Awareness
- Progressing Posthumous Recognition of Organ and Tissue Donation Status through the NSW Attorney General.
- Introduction of tile on Service NSW App & email with link to OTA National Register 5.2 million people receiving and email from the NSW government encouraging registration to become organ donors and discuss the importance of Next of Kin Consent when considering organ donation.
- Addition of link to OTA National Register on other NSW Govt web sites
- Reintroduction of Donor Registration onto Drivers Licence renewal and applications
- Review of NSW School Curriculum to include Organ & Tissue Awareness
- Utilisation of Government Communications media in public places to carry Next of Kin and Organ and Tissue Donation messages.

Victoria

- Consideration being given to inclusion of Link on Service VIC
- Liaising with Mr Alan Turner of Zaidee's Foundation to learn more about the foundation and the Zaidee;s Junior Donor Cards

NT

- Liaising with DonateLife NT

Tasmania

- Correspondence with Premier Liaising Gutwein and his department
- Liaising with DonateLife Tasmania.

QLD

- Correspondence with Minister AYvette D'Ath MP.

National

- Assisting in securing additional funding for the WTG in Perth.
- Application to Lyfebulb Innovation Challenge for Sweetest Gift – International Finalist
- Application for Community Grant for Herd of Hope through electorate of New England NSW to be applied across national activity of the charity
- Advocating to St John Australia on Posthumous recognition including directly with Brendan Maher and the Knights of the Order of St John.
- Support and promotion of:
 - Transplant Australia, World Transplant Games Federation
 - DonateLife Week,
 - Jersey Day,
 - Donor Families Australia - Donor Heroes Night 2022& 2023
 - DonateLife Thankyou Day
 -

Member of Community Groups

- Liver Transplant Friends, Au
- Transplant Active Community
- Transplant Hub
- Transplant International TRIO
- Lyfebulb Interbational
- Kids Liver Disease & Transplant
- Kidney Transplants & Donors Au
- Heart & Lung Transplants Au

My focus is on improving Legislation, Education and Communication to increase awareness amongst families and next of kin about the decision they may be unfortunate enough to have to make when confronted with the sudden loss of a loved one.

Initiatives the Inquiry should address.

f) **Opt in versus Opt Out** (registered consent versus deemed consent)

The focus of your inquiry is to determine the best ways for raising the rates of Organ & Tissue Donation in Western Australia. The current registry of consent is an opt-in system where Australians register their intent to be an organ donor. The act of registration does not bind the individual to becoming a donor, if the pass in the right circumstances. To be an organ donor of the vital lifesaving organs, one must die in peculiar circumstances and be either on life support or be able to be placed on life support to sustain the viability of soft tissue organs. Currently only 36% or around 7.5 million Australians have registered their intention to be an organ donor. (In WA that number is 38%) 4.8 million Australians are minors and therefore cannot be on the register, which leaves around 13.7 million unregistered Adults but a total of 18.5 million Australians who have not indicated intent to become an organ donor.

In the clinical environment, when someone is at their mortal journey's end, whether they are a registered donor or not, they will be considered medically for suitability as a donor. (The criteria for this can be accessed by the committee so I will not detail it in this submission). If they are considered to be suitable for donation for an identified patient or a number of identified patients, the protocols to seek consent from next of kin will then be activated. Next of Kin Consent is necessary for any transplant to take place. In WA the rate of consent is just 50%. That is half the families asked whether the potential donor is registered or not say NO.

Many have suggested a better system of registration would be opt-out or deemed consent. Without going into the legalities of deemed versus opted consent, the requirement for next of kin consent would not be removed from the clinical process. This is proven out in the [UK example](#).

g) Absolute Consent

To reduce the requirement of Next of Kin Consent, the registration process could be amended to offer the registrant the option to exercise absolute consent.

This consent would lay down the legal conditions and terms that would enable, adult Australians the right to exercise an absolute determination to be an Organ Donor should their life end in a hospital whilst on life support.

The ethics and enforceability of such a measure would need to be weighed against the negative connotations such an option would face.

Even with deemed consent, being in place with Next of Kin consent rates being at 50% in WA in 2022, the likely increase in rates would be minimal and may even invoke a further decline.

h) Next of Kin Consent

In all cases where a patient who is on life support and either death is determined to have occurred, the family must be consulted as to the stages of dealing with the persons processing.

This includes the determination of whether the person is deemed suitable for organ donation, in circumstances where suitable recipients can also be identified.

Next of Kin Consent rates will be impacted on by many factors, however the key factor is the psychological state of the identified next of kin. Grief is a powerful determinant in how any individual will respond when learning their loved one has passed.

The recent Organ and Tissue Authority report indicates that the method of communications with the potential donor family when Next of Kin Consent is being sought. The report suggests that when 56% of families provide next of kin when a Donation Specialist Nurse is involved in seeking consent. This number falls to just 23% where there is no specialist transplant nurse involved. Donation nurses were involved in 80% of all consent requests. These consent rates are across both registered and non-registered deceased potential donors.

So whilst the involvement of specialist transplant nurses provides a better conversion rate, it is the conclusion that prior knowledge of the individual's intention of a previous discussion with next of kin about the family's position on organ donation is a greater contributing factor in securing Next of Kin Consent,

Therefore regardless of whether people register voluntarily (Opt-in) , or whether the system was moved to deemed consent or Opt-out, next of kin consent will be required, so more needs to be done to communicate and educate all Australians about the importance of next of kin consent.

i) Drivers Licence Registration

Removed as a part of the Organ & Tissue Authorities formation, the Authority are now wanting states to make the investment financially and logistically to reintroduce the registration to the national register on drivers' licences.

Given the time periods involved this retrograde step will be expensive and time consuming taking many years to impact on both registration rates and increases in Next of Kin Consent Rates.

The benefits of communication to new drivers and drivers renewing their licences can be better achieved through other initiatives. Further given the percentage of adults who do not have drivers licenses this initiative is not a complete solution to the registration of intent and if introduced would still require NEXT of Kin Consent to be sought at the time in WA in any one year that potentially 84 people became eligible donors.

There is no correlation proven between the number of registered intent donors and actual donors. Despite the database of registered intent increasing actual donations is not.

i) Electronic Registration via WA Portals

The use of electronic portals and websites accessed by Western Australians of all ages to register intent will reach more potential donors than the reintroduction of Driver's License Registration

j) Other initiatives the Inquiry should consider to increase donation and transplant rates.

i) Posthumous Recognition of Deceased Donor Status.

(1) The NHS and St John International award organ and tissue donors a posthumous award in recognition of their donation.

<https://www.odt.nhs.uk/statistics-and-reports/order-of-st-john-awards-annual-report/>

(2) The [Consent](#) rates in the UK since the posthumous recognition have been above 60%

ii) Amendments to the Privacy Section 34c of the HTTA Act

(1) Amendments to the Privacy Section 34c of the HTTA act to include “senior next of kin consent”

iii) Hospital processes procedures and reporting

(1) Standardising the identification, and reporting processes of all donation opportunities and ensure all hospitals using same reporting standards.

(2) Clinician education in empathy and next of kin communications.

iv) Community Education across all ages.

(1) [A Gift Before I Go](#)

(2) [Zaidee's](#) Chasing Rainbows –

In 2004 Zaidee Turner suddenly died at 7 years of age, due to a burst blood vessel in her brain (a cerebral aneurism). Zaidee's family made the decision to donate her organs and tissues at the Royal Children's Hospital in Melbourne and, as a result, a total of seven people had their lives improved or saved. Her liver went to an 8 year old girl, a mother received both kidneys, 2 children received a cornea each, a baby received a heart valve and another baby received a heart patch.

(3) Zaidee's Kids Donor Card as per Victoria

(a) In the year 2006 Zaidee's Kids Donor Card were launched for children and families to have the discussion and understanding their child's wishes. Since then over 760,000 of these cards have been issued to children for free.

v) Support for Awareness beyond OTA DonateLife week

vi) Harmonisation of HTTA with other organ and tissue and transplant legislation across Australia

vii) Capped contribution to Funeral expenses for Deceased Donor Families.

(1) In 2021 Next of Kin Consent rates in WA were above the national average at 58%. However, in 2022 this fell dramatically to just 50%. Fewer deceased donors resulting in many fewer lifesaving transplants. Also, WA experienced fewer people registering their donor intent. Another worry is the reduction in dpmp falling from 16.4 to just 15.4.

An initiative I would like to put forward for the Friends of Parliament in WA to consider is the state contributing to the funeral expenses of deceased Organ Donors to ease the burden on Donor Families.

Australia trails the world and WA trails the nation in next of kin consent for deceased organ donation.

The initiative is a financial contribution of \$5000 towards funeral expenses for all deceased organ donors' families. The \$5000 is capped and is strictly for funeral expenses.

In 2022 there were only 43 deceased donors in WA. If this number was higher more lives would have been saved. Of 86 requests only 43 families gave consent. 50%! If that number was 75% it would

represent 65 families saying yes and if we could increase it to 85% of families saying yes we could realise around 30 donors.

Based on 75 deceased donations the cost per year to Western Australia would be just \$375,000 pa.

The savings in lives and ongoing medical costs could be significant. If each donor saved 5 lives, the number of lives saved is 375 or just \$1000 per life.

There are some obvious sensitivities associated with the topic.

Is the state buying organs? Will health givers try less to save the lives of potential donors? Is it ethical? The answer to these questions and many more needs to be discussed but the idea should be explored.

I have done some further investigation into the ethics of the funeral expense proposal and wanted share a couple of reference sites.

The UK introduced [The Children's Funeral Fund for England \(CFF\)](#)

Whilst the concept of covering funeral expenses at a capped amount was suggested by [Nuffield Council Of Ethics](#) in the UK, it has yet to receive political support in any jurisdiction. I have included a copy of the report and couple of links to different [articles](#) covering the discussion at the time.

<https://www.nbcnews.com/health/health-news/dead-serious-free-funerals-boost-organ-donation-flna1c945411>

<https://theconversation.com/free-funerals-for-organ-donors-are-donation-incentives-unethical-3809>

All legislation across Australia requires Next of Kin Consent for any transplant to take place whether a person has opted in on the national register or not.

Whilst in SA, this heartbreaking [story of Odetta's family](#) and their generosity and selflessness, to give Next of Kin consent for her organs to be donated to save other people's lives, is inspirational.