

LEGISLATIVE ASSEMBLY'S LEGAL AND SOCIAL ISSUES COMMITTEE

INQUIRY INTO INCREASING THE NUMBER OF REGISTERED ORGAN AND TISSUE DONORS

ANSWERS TO QUESTIONS ON NOTICE - June 2023

Question 1

Refer to page 17

Chair asked: 'Regarding historical funding, I am very happy if you want to take this on notice, but it would be good to get a snapshot of funding since 2009. If you could just detail the funding that has been provided to the Organ and Tissue Authority and how that has been broken down to different states'

Question: Provide detail of the funding that has been provided to the OTA since 2009 and how it has been broken down to the jurisdictions.

Answer:

- The OTA administers grants to support state and territory governments to deliver organ
 donation services. Funding is provided via multi-year head agreements and associated
 multi-year funding schedules. This funding supports a DonateLife agency in each state
 and territory, as well as dedicated donation specialist staff in hospitals. The OTA
 contributed a total \$31.2 million in funding to states and territories for this purpose in
 2022-23.
- In addition, the OTA provides a contribution towards the costs associated with organ donation activity through Organ Donation Hospital Support Funding (ODHSF). This funding is based on actual and intended organ donors, and the cost of transferring a potential donor from a regional hospital to a larger hospital solely for the purpose of donation. The OTA provided a total of \$6.7 million of ODHSF to states and territories for 2022-23.
- The Organ and Tissue Authority (OTA) is a small agency with limited resources. We have limited the following analysis to the past five years. For historical financial information please refer to our annual reports which are available through the DonateLife web page.



Figure 1 – Breakdown of grants paid to state and territory governments

Funding is provided via multi-year head agreements and associated multi-year funding schedules with each state and territory. Funding amounts may vary between years due to donation activities, indexation, and payment timing.

Year	Funding (\$m)	VIC	ACT	NSW	QLD	SA	WA	TAS	NT	Total
2022-23	S&T Grants	7.682	1.151	8.398	5.282	2.989	3.156	1.374	1.211	31.243
	ODHSF	1.890	0.110	1.750	1.350	0.638	0.670	0.240	0.020	6.668
	Total	9.572	1.261	10.148	6.632	3.627	3.826	1.614	1.231	37.911
2021-22	S&T Grants	7.495	1.124	7.837	5.019	2.926	2.926	1.341	1.181	29.849
	ODHSF	1.680	0.100	1.470	1.130	0.580	0.648	0.160	0.020	5.788
	Total	9.175	1.224	9.307	6.149	3.506	3.574	1.501	1.201	35.637
2020-21	S&T Grants	7.045	1.117	7.729	4.932	2.894	2.955	1.260	1.293	29.225
	ODHSF	1.770	0.110	1.530	1.330	0.660	0.600	0.148	0.030	6.178
	Total	8.815	1.227	9.259	6.262	3.554	3.555	1.408	1.323	35.403
2019-20	S&T Grants	7.663	1.181	8.260	5.176	3.026	3.281	1.472	1.187	31.247
	ODHSF	2.000	0.180	1.600	1.360	0.620	0.584	0.188	0.020	6.552
	Total	9.663	1.361	9.860	6.536	3.646	3.865	1.660	1.207	37.799
2018-19	S&T Grants	7.280	1.142	6.125	4.905	2.899	3.129	1.301	1.026	27.809
	ODHSF	2.590	0.140	1.900	1.210	0.680	0.712	0.190	0.050	7.472
	Total	9.870	1.282	8.025	6.115	3.579	3.841	1.491	1.076	35.281



Refer to page 19

In response to Cindy McLEISH 'Previously parents could register their children as an intent on the register—I am aware of that. I would need to take on notice when that actually changed, but the register as it stands now you have to be 16 or over to register.'

Question: In what year did the process change so that parents could no longer register their children's intent on the AODR?

Answer:

 The OTA recommends this question be referred to the Department of Health and Aged Care (the department). The department has responsibility for developing Commonwealth policy on issues relating to the legal framework for determining consent to organ and tissue donation, including the process by which consent/intent information is collected and recorded in the Australian Organ Donor Register (AODR).



Refer to page 25

Annabelle CLEELAND asked: 'With the information from Cindy around the paediatric consent for parents and donor registration, when did that occur? And who was responsible for that decision? And was it a legislative reason or was it...'

Questions:

- 1) In what year did the process change so that parents could no longer register their children's intent on the AODR?
- 2) Who was responsible for the decision to change the process?
- 3) What was the reason for the change?

Answer:

 The OTA recommends this question be referred to the Department of Health and Aged Care (the department). The department has responsibility for developing Commonwealth policy on issues relating to the legal framework for determining consent to organ and tissue donation, including the process by which consent/intent information is collected and recorded in the Australian Organ Donor Register (AODR).



Refer to page 30

Annabelle CLEELAND asked: 'Have you been able to reach hearing-impaired people through your awareness and communications?'

Question: How has the OTA been able to reach hearing-impaired people through its awareness and communications?

Answer:

- In 2017 the OTA awarded a Community Awareness Grant of \$22,000 to the Victorian Deaf Society (VicDeaf, now known as Expression Australia) to develop a series of videos to educate the deaf community about organ and tissue donation.
- The project involved:
 - running focus groups with the deaf community to understand their knowledge of organ and tissue donation
 - developing video resources (in Auslan) about how to discuss donation with your family, and sharing personal stories from those in the deaf community whose lives have been impacted by donation
 - presenting to the deaf community in Melbourne about organ and tissue donation in Auslan.
- These video resources are still available on the DonateLife YouTube channel (<u>Make your decision known</u>; <u>Have you decided</u>; <u>Meg's story</u>; <u>Medina's story</u>) and have been shared across social media.
- As best practice, we add subtitles to the OTA's new video assets, and alt text to images, graphs and videos on the DonateLife website to meet accessibility requirements for screen readers.



Refer to page 18

Chair asked: 'could the Organ and Tissue Authority provide a list of organisations that have received community awareness related grants like you mentioned since the OTA's inception. Is that possible?'

Question: Provide a list of organisations that have received community awareness related grants since 2009.

Answer:

Grants of \$25,000 and above are provided below between 2009-2023.

For additional grant information please refer to Grant Connect at https://help.grants.gov.au/ or the news and events section of the OTA website at https://www.donatelife.gov.au/news-events.

- Alagna Films
- Alice Springs Hospital
- Artback NT
- Asian Australia Community Services Inc
- Australian Men's Shed Association
- Australian Multicultural Foundation
- Barwon Health
- Centre for Health Initiatives, University of Wollongong
- Coen Ashton Foundation
- Community Advisory Council for DonateLife WA OneLifeWA (auspiced by Synergy Acquisitions Pty Ltd)
- Community Broadcasting Association of Australia
- Community Migrant Resource Centre
- Convenience Advertising
- Cystic Fibrosis Australia
- Deakin University
- Donor Mate
- Ethnic Broadcasting Association of Queensland
- Federation of Ethnic Communities' Councils of Australia
- Footscray Football Club Limited trading as Western Bulldogs
- General Practice NSW
- Gift of Life Inc
- Greater Eastern Primary Health





- Griffith University
- Guest Consulting
- Health Consumers Council WA
- · Heart and Lung Transplant Trust Victoria
- Hunter Hospital
- Islamic Council of Victoria
- Jayden Cummins
- La Trobe University
- Little Rocket
- Make Mate
- Medical Channel Pty Ltd
- Melbourne Heart Football Club
- Migration Council Australia
- Multicultural Centre for Women's Health
- Multicultural Communities Council of Western Australia
- Multicultural Services Centre of Western Australia
- Nathan Gremmo Community Fund Inc
- National Rugby League
- Nationwide News Pty Limited
- Netball Australia
- Netball WA
- Northern Hospital
- Northern NSW Local Health District
- NSW Central West Division of General Practice Ltd
- Organ Donation and Transplant Foundation of WA
- Osborne GP Network
- Pixel 42
- Podshape Podcasting
- Pole Depot Community Centre
- Queensland Remote Aboriginal Media
- Regional development Australia Far North Queensland and Torres Strait
- Royal Institution of Australia
- Savage Films Pty Ltd
- Silverpod Productions
- South Eastern Health Providers Association
- Southern Cross University
- St Vincent's Hospital
- The Groundswell Project Inc
- The Trustee for Australian Professional Leagues Trust
- The Trustee for The Cool Australia Trust





- The University of Newcastle
- Tonic Health Media
- Valimanda Pty Ltd (Melbourne Storm)
- Vic Regional HSN Group
- Vic Regional Nurse Donation Specialist Group
- Victorian Metropolitan Nurse Donation Specialist Group
- Wattle Street



Refer to pages 30-31

CHAIR asked:

The CHAIR: Just very quickly, and I am very happy for you to take this on notice: is the OTA aware of any research being undertaken into some current barriers to registering to become a donor?

Brianna ELMS: Yes. We have got some in the market at the moment.

Lucinda BARRY: It is our research.

The CHAIR: Your own research that you have commissioned? Fantastic.

Lucinda BARRY: We have funded research nationally to look at that, definitely.

The CHAIR: Is that something you can share with the Committee when it is completed?

Brianna ELMS: Yes, once it is done—absolutely.'

The CHAIR: Great. And if there is any other research that you are aware of that would be beneficial to the inquiry, the Committee would really appreciate seeing that too.

Lucinda BARRY: I will send you some links. (pp. 30-31).

Question:

1) Provide details of any research, the OTA is aware of, being undertaken into current barriers to registering to become a donor, that would be beneficial to the inquiry.

Answer:

- The OTA appointed FiftyFive5 in April 2023 following an open and competitive procurement process. FiftyFive5 will conduct market research to better understand current community attitudes and perceptions aligned to the <u>OTA's Strategy</u> "build support for donation" goals and objectives.
- The research will build on existing data, behavioural insights and research reports, is expected to be finalised by end 2023, and a copy of the report can be provided.

Question:

1) And if there is any other research that you are aware of that would be beneficial to the inquiry, the Committee would really appreciate seeing that too.



Answer:

Research projects 2020-2023

- Driving organ and tissue donation behavioural change; FiftyFive5, 2023 (underway)
- DonateLife brand study; YouGov, 2021, 2022 and 2023
- Exploring young people's knowledge, attitudes and perceptions of organ donation; La Trobe University, 2022
- Insights into relevant beliefs, values and practices associated with organ donation and registration in the Indian and Bangladeshi community in Sydney; Southern Cross University, 2022
- <u>Using behavioural insights to improve organ and tissue donor registration among young</u>
 <u>adults</u>; Behavioural Economics Team of the Australian Government, Department of the
 Prime Minister and Cabinet, 2021
- Community awareness survey; Kantar / Colmar Brunton, 2020