

# ARTICLE IN REVIEW:

## Positive correlation between tissue donation for medical research and families' attitude toward donation in general

**PUBLICATION:** Human Genetics, January 2018

**TITLE:** Authorization of tissues from deceased patients for genetic research<sup>1</sup>

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**STUDY DESIGN:** Ethical, Legal, and Social Issues (ELSI) Substudy

**SUMMARY:** Tissue donation for biomedical research is essential to understanding disease pathology and developing new treatments. The Genotype-Tissue Expression (GTEx) Project examines the relationship between gene expression and common diseases in biospecimens collected from healthy organ and tissue donors. This study evaluated the factors that contributed to the family decision makers' (FDMs) choice to donate tissue for biomedical research, in particular to the GTEx project, as well as the characteristics of the tissue requestors (TRs) who interacted with the families. The study included 413 FDMs, 317 (76.8%) of whom donated to GTEx and 96 (23.2%) who did not, and 99 TRs who completed a total of 309 surveys. FDM consent to GTEx donation was associated with positive attitudes about medical research ( $p < 0.05$ ), comfort with tissue donation ( $p < 0.05$ ), endorsement of policies promoting biobanking ( $p < 0.05$ ), lack of concern regarding a breach of confidentiality ( $p < 0.05$ ), and prior authorization to solid organ donation ( $p < 0.001$ ). TR sociodemographics (female gender,  $p < 0.05$ ; white race,  $p < 0.05$ ), intensity of discussing research-related topics with FDMs (time and number of topics discussed) ( $p < 0.0001$ ), and comfort with the GTEx authorization process ( $p < 0.01$ ) were all associated with FDM donation to GTEx. Understanding predictors of FDMs' decisions to donate tissue for biomedical research will guide future education efforts, with the ultimate goal of increasing tissue donation for research.

### Families' attitudes correlated with tissue donation for research:

Positive attitudes toward tissue and organ donation in general; medical research; and policies to promote biobanking were all associated with authorization for tissue donation for the GTEx project.

### Requestors' characteristics correlated with tissue donation for research:

Sociodemographics of tissue requestors and comfort discussing biomedical research-related topics were positively associated with gaining authorization for tissue donation for the GTEx project.

### Future education efforts may increase tissue donation for research:

These results indicate that an understanding of tissue donation for biomedical research correlates positively with donation to the GTEx project. Future education efforts on medical research may, thus, help to increase tissue donation for research.

## Family Decision Makers and Tissue Requestor positive predictors for tissue donation to GTEx

FDM Factors	OR* (confidence limits)	p value	TR Factors	OR (confidence limits)	p value
Positive attitude toward medical research	1.1 (1.02-1.15)	<0.05	Sociodemographic variables (gender, race)	Female: 3.57 (1.14-11.2) White: 4.97 (1.34-18.5)	<0.05
Comfort with tissue donation	1.24 (1.01-1.53)	<0.05	Number of topics discussed with FDMs	57.9 (6.53-99.9)	<0.0001
Support for policies promoting biobanking	1.35 (1.02-1.78)	<0.05			
Prior solid organ donation authorization	3.17 (1.85-5.43)	<0.001	Comfort with GTEx authorization process with hospital staff	1.61 (1.13-2.3)	<0.01

\*OR = odds ratio. Table created from data presented in Table 5.<sup>1</sup>

### Reference:

1. Wilson-Genderson M, Barker KL, Gardiner HM, Mosavel M, Thomas J, Siminoff LA. Authorization of tissues from deceased patients for genetic research. Hum Genet. 2018;137(1):63-71. doi:10.1007/s00439-017-1855-y

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