

Communication Can Increase Research Donation Consent Rates

Human tissues have become increasingly important for pre-clinical medical research. While this provides many benefits – including more accurate and relevant results to fuel the development of enhanced drug therapies – it also brings new challenges. Shortages of human tissues have become common, highlighting the need to boost awareness among potential donors, and to improve communication with families who are in a position to consent.

Processes have been evolving to encourage donation throughout the United States, including changes to the Uniform Anatomical Gift Act in 2006 to encourage gifts for research. Computerized donor registries across the country have also made a difference.

Still, problems remain. There is less awareness of tissue donation in general, compared to organ donation – and still less understanding of research donation. Donation professionals are often in a position to discuss tissue donation only by phone, instead of in person, which can add another layer of complexity to the communication process. Family consent, followed by a lengthy interview process to answer question about the donor's history and lifestyle, are crucial to make tissue donation a reality for either transplantation or research.

Every year, thousands of potential donor opportunities are lost. The Determinants of Family Consent to Tissue Donation study – one of the largest of its kind in the nation – offers insight into what can help turn this situation around. The findings showed that communication, centered on empathy and connection, is key. Beneficial practices include discussing issues that are important to families, such as:

- Tissue donation will not negatively impact funeral plans.
- No donation-related costs will be passed on to a donor's loved ones.
- Processes are in place to ensure equity, or fairness of how gifts are distributed.

The study found that families were 17 times more likely to donate when these important issues were covered by donation professionals. The findings also noted that discussions lasting longer than five minutes were correlated with higher rates of consent. Donation professionals were more successful, and kept people on the phone longer, when they were reassuring, repeated information, and expressed gratitude and empathy.

LifeNet Health has long been a leader in developing best practices to guide donor and family consent. Current initiatives include a campaign to encourage the public to discuss organ and tissue donation ahead of time as a foundational step to increasing support. In addition, we continuously evolve our training methods to help our donation professionals to handle family discussions with empathy and respect. On the research front, our biospecimens are supported by strong practices to ensure donor families are fully informed, even referencing specific projects when necessary. Our ethical consent processes are centered on a deep commitment to honor donors and their families. We encourage researchers to consider the issue of ethical consent when partnering with a biospecimen provider.

Learn more about this issue by viewing our <u>Considerations for Tissue Donation Authorization webinar</u>.

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