



The Organization for Transplant Professionals

NATCO, THE ORGANIZATION FOR TRANSPLANT PROFESSIONALS POSITION STATEMENT

DONOR REGISTRIES

Statement of the Problem:

Since 1968, the Uniform Anatomical Gift Act (UAGA) has provided the legal means for adults to document a choice for organ donation via a standard document of gift (e.g., donor card), with the intent that such desire to donate will take place at the time of the individual's death. Amended in 1972, the UAGA also provided an option for family members to make a donation decision on behalf of a deceased loved one in the absence of such documentation completed by the deceased before death. An "opt-in" system for donation, this act requires would-be donors to take specific action (e.g., signing a donor card; informing one's family, etc.) in order to solidify the donation choice.

Paper donor cards in various forms and from many agencies became available with the adoption of the UAGA in all 50 states but technological capabilities limited access to such documents after donor wishes were recorded. In the 1990's, however, rapid electronic data storage, filing, and retrieval, replete with security systems have expanded one's consent options to include electronic informed consent for organ donation. For example, adults can record their decision to donate in a secure Internet database. Those with appropriate credentials (e.g., identification and passwords) can verify an individual's wishes in a matter of seconds. In the future, the potential donor's phenotypic information could also be stored within such an electronic system. The implications are profound, but as of yet, there is no national system in the United States for recording organ and tissue donation preferences, rather each registry is unique.

Policy:

NATCO fully recognizes the right to make personal choices -- including the choice to donate organs -- and fully supports the autonomy individuals have to record such decisions. NATCO believes that an anatomical gift that is not revoked by the donor before death is irrevocable and does not require the consent or concurrence of any person after the donor's death (unless the donor is a unemancipated minor). In effect, the deceased has already made an effective donation of their gift to the organ procurement organization and next of kin cannot interfere with the donation that has been made. NATCO commends those who are honoring the wishes of donors while keeping families of donors

informed throughout the process. This includes having documentary evidence of an individual's donation intent, thus fostering transparency for donor families.

NATCO encourages the establishment of standards for donor registries in an effort to foster improved access by procurement organizations to documents in donor registries, medical records, and records of a state motor vehicle department. This access will make it easier for procurement organizations to determine whether an individual is a donor

NATCO believes extensive research is needed to link individual state or other registries so that transplant professionals can quickly and easily, under the protection of secure cyber systems, determine the donation choice of the deceased. This said, NATCO does not support implementing a national registry in the United States at this time, due to the logistical problems of state registries interfacing into one system. Any system generated needs to be validated to ensure that the data contained is both accurate and secure. Most importantly, the system needs to foster transparency and public trust.

NATCO believes there is potential in building registries of potential live donors to expedite transplantation of viable, vital organs; however, such is a very complex undertaking that requires extensive research. Ethical issues that need to be considered include ensuring donor altruism, as well as, addressing donor screening, safety, and privacy issues.

NATCO supports and recommends ongoing collection and careful analysis of all donation authorizations in order to gauge the effectiveness of public education efforts. NATCO also encourages ongoing dialogue among the Organ Procurement Transplant Network, the Division of Transplantation of the federal government, and all related transplant specialists and the public to swiftly design and implement registries that simplify the process of choosing donation for oneself, and to further identify ways to allow communication among those registries. NATCO also supports Congressional support (funding) of state registries to allow local experts to customize donor registries to meet the needs of their residents.

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