American Medical Association

Physicians dedicated to the health of America

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February 17, 2004

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Chair of Study Committee
Virginia Commissioner
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Dear Mr. Ring:

Thank you for your letter of November 21, 2003, to the American Medical Association (AMA), in which you invited input from the Association regarding amendments to the 1987 Uniform Anatomical Gift Act (subsequently "the Act" or "UAGA") that might facilitate donation and procuring of organs and tissue for transplantation.

The AMA has extensive policy supporting organ donation. Many of these policies were developed with the intent to increase organ donation within a paradigm of altruism. More recently, the AMA also has begun recommending that innovative approaches – even those that might fall outside this paradigm, including the acceptability of financial incentives – be studied to determine their appropriateness and impact on donation.

We hope that the Study Committee also is seeking input from the American Society of Transplant Surgeons, the American College of Surgeons, and the Renal Physicians Association, among others, as well as from specific state medical societies, including the Texas Medical Association, which has distinguished itself through its efforts toward improving organ and tissue donation. If not, the AMA would be ready to assist you in seeking input from these various medical societies.

With regard to the 1987 Act, we have identified several areas where amendments should be considered to facilitate donation and procuring of organs and tissue. These are:

Incentives

The 1987 Act strictly prohibits the provision of any valuable considerations to organ donors. While the AMA agrees that it is not ethical to participate in a procedure to enable a living donor to receive payment (other than for the reimbursement of expenses incurred in connection with removal), it believes that innovative approaches to encourage organ donation should be studied, including the conduct of ethically designed research studies of financial incentives in the context of cadaveric organ donation. Such studies, of course, would require congressional action to waive the prohibition against valuable considerations in the 1984 National Organ Transplantation Act, as well as adequate safeguards to ensure that voluntariness of donation was not compromised and that allocation of organs continued to be based on ethically appropriate criteria related to medical need.

Should these innovative methods, including financial incentives, increase the number of cadaveric donations, they could help supplement existing initiatives and address the current shortage of transplantable organs. However, the only way to know is to measure their effect on donation rates and on public perception of the transplant enterprise and of the meaning of organ donation.

We do recommend that the UAGA be revised at this time so that should study results demonstrate the value of incentives in increasing donation rates, the Act would not prohibit them.

Such an amendment is likely to be met with disagreement from parties that maintain that the only ethical motivation for organ donation is altruism. However, it is obvious that in our current system, which relies on altruism alone, the demand for transplantable organs is not being met.

Consent

Binding Consent

Despite attempts to clarify consent, it remains true that few organs are donated solely on the basis of donor cards or written directives. It is typical that even when a person clearly documented wishes to donate, family members are contacted for their permission prior to the retrieval of organs. The AMA would recommend an amendment that would require honoring deceased individuals wishes by making donation preferences, as documented on drivers' licenses or advance directives, enforceable and providing physicians who adhere to these wishes legal immunity.

Such an amendment could be met with resistance on the basis that family members disagree with the deceased's decision. However, respecting individuals' informed decisions - even after their death - is the pillar of our common medical and legal ethos.

Presumed Consent and Mandated Choice

AMA policy recognizes that presumed consent is an option worth exploring, as a strategy for increasing organ donation, but only if certain safeguards could be implemented (e.g., broader education of the public regarding organ donation and the existence of a presumed consent system and infrastructure to document individuals' choice to opt out).

Such a system likely would be met with opposition in a country that places great emphasis on autonomy and individuality. A more acceptable system might be one of mandated choice in which individuals are required to express their preferences regarding organ donation when renewing their drivers licenses or performing some other state-mandated task.

Repositories

One step towards strengthening the importance of consent would be to create nationally coordinated donor repositories that contain information regarding individuals who have indicated a preference. If these could be updated and accessed easily by appropriate parties, they likely would receive broad support.

Request Process

Required training – and possibly certification - for individuals who approach patients or their families regarding the possibility of organ and tissue donation could help facilitate the request process and improve favorable response rates. Indeed, patients and more often their families usually are asked about donation at a very difficult and emotional time, when compassion is essential A revised UAGA could specify a heightened standard of preparation for individuals involved in the request process. However, there likely would be initial resistance to additional training.

Also, specific clarification is needed regarding who can make an organ donation request. In 1987 an attempt was made to clarify roles and responsibilities (and to make licenses more binding), but the current act remains unclear. Too often, physicians are removed from the donation request process. This is problematic as physicians are an important "trust agent" within the context of care and best able to facilitate a request (e.g., make the request themselves or facilitate transition to the designated requestor).

Recommendations from a recent AMA/HRSA study suggest the need to explore the use of designated physician-requestors, to adequately certify designated requestors, and to clarify roles and responsibilities and develop protocols and best practices that place the request in the context of end-of-life decision-making (including the use of advance directives, etc.).

While a better definition of roles may facilitate donation, ongoing turf issues between hospital and OPO staff will need to be resolved.

Non Heart Beating Donors

Given the increasing need for donor organs, protocols for procurement following cardiac death have been developed. However, the 1987 UAGA is silent regarding non heart beating donors. This method of procurement, while it remains controversial, is in use in various parts of the country. As such, it deserves to be legally addressed.

Living Organ Donation

The number of living organ donors in the United States exceeded that of cadaveric organ donors for the first time in 2001. For this reason, we believe it is important that a revised UAGA should address donation in this context. Such an amendment could be contentious. Indeed, living organ donation raises unique ethical considerations, not the least of which is whether physicians should subject potential donors to the risks of surgery when there is no physical benefit to be gained. A section on living organ donation in the Act could introduce standardization to a practice that is largely unregulated.

The AMA's Council on Ethical and Judicial Affairs currently is developing a report regarding ethical guidelines for living organ transplantation. If you would like further information on the status of this work, please contact Sara Taub (312-464-4822), staff to the Council on Ethical and Judicial Affairs.

We hope that you will consider these recommendations for amendments to the 1987 Uniform Anatomical Gift Act. We would be pleased, not only to provide you with additional input if you elect to proceed with revisions to the Act, but also to offer the expertise of a transplant physician from the AMA's Council on Ethical and Judicial Affairs to assist your Study Committee as you see appropriate. The AMA welcomes the opportunity to work with the National Conference of Commissioners on Uniform State Laws in efforts that directly affect the health of Americans.

It is a privilege to offer early direction to the work of the Study Committee.

Sincerely,

Michael D. Maves, MD, MBA