UNOS DONATE LIFE

UNITED NETWORK FOR ORGAN SHARING

Testimony of Dr. Timothy Pruett to Congressional Hearing, Sept. 25, 2007

My name is Timothy Pruett. I am the Strickler Family Professor of Transplantation and Surgery at the University of Virginia and the current President of the Organ Procurement and Transplantation Network/United Network for Organ Sharing. UNOS is the nonprofit organization which operates the OPTN by contract with HRSA. It is not my intent to speak as an official representative of the transplant community, but rather for the patients and families that I have seen as an individual providing transplantation care for over 20 years.

For the most part, people of all ages with end stage kidney, liver, heart and lung problems live longer and better with an organ transplant than with other forms of medical support. Unfortunately, the numbers of people waiting for organs greatly outstrips the organ availability from deceased individuals. Because of an increasing wait time and the continuing gap between the numbers of people waiting and organs available, a number of Americans step forward each year to donate an organ to another person. Although many types of organs can be transplanted with live organs, this act of amazing generosity is most frequent for those that need and receive kidney transplants. From a system operations perspective, a kidney from a live donor is best: it lasts longer in the recipient, it is an easier operation to plan for the recipient and the medical center and it functions more quickly and reliably than one from a deceased donor. In short, if you needed a kidney, you would want to receive one from someone who was alive and not dead.

The first kidney transplant ever performed came from a live donor. In 2006, over 30% of the kidneys transplanted in the US came from live organ donors. It is a form of organ donation that our people have embraced for 60 years. The executive and legislative branches of the government have recently weighed in regarding the value of live organ donation. Because there are many instances where Americans are willing to donate, but biology gets in the way, a variety of methods of "paired donation" have been proposed to increase this type of organ transplantation. Congress has recently addressed the issue through legislation and is on the verge of passing H.R. 710, the bill named for former Representative Charlie Norwood. That bill officially provides what the Department of Justice has recently approved in memo form: that paired donation between live donors and recipients does not constitute valuable consideration and is therefore legal under Sec. 301 of NOTA.

In 2006, a directive was published in the Federal Register (Vol. 71, No. 116, 34946) instructing the OPTN to "develop policies regarding living organ donors and living organ recipients, including policies for the equitable allocation of living donor organs, in accordance with section 121.8 of the [OPTN] Final Rule". It is clear that the value of living organ donation and transplantation is an activity to be encouraged from the perspective of those in need of receiving organs, the medical community, those who reimburse organ transplantation and the government and oversight community.

The live donor does an extraordinary act; lying down on an operating room table, giving up a piece of oneself for another person and placing one's health and safety in the hands of doctors and nurses when there will be no direct medical benefit for that person. Our society (and treasury) gets a great deal of benefit from this form of generosity. Unfortunately, the pain of recovery from the procedure of removing a kidney (or any other organ) is often not the only form of pain that the donor suffers. Financial pain is also common. Significant financial disincentive to be an organ donor exists in the U.S. This comes in many forms: lost wages of the donor and family support members; temporary change in the ability to perform one's job during the recovery period; travel costs incurred during the evaluation to be a donor; potential ability to obtain and collect insurance benefits as a consequence of the donation process or, in a worst case scenario, permanent disability, need for transplantation or even death.

We have no safety net for those who want to donate organs. Fortunately, kidney donation is relatively safe, with a very low risk of death and minimal long-term morbidity, but there are multiple reports in the transplant and lay literature -- and even more personal anecdotes -- of significant financial hardship associated with the live organ donation process. This is particularly true for those individuals with personal incomes at the lower end of our financial earnings spectrum. Although the costs of the medical workup are covered by the recipient's payor, for the person without means, the personal savings, family's or employer's ability to help defray the additional expenses just don't exist.

As a society, we gain much in quality of life and productivity from the recipients and financial benefit through the acts of generosity that occur daily through live organ donation. I recently gave a talk at the International Liver Transplantation Society on "Ethical Aspects of Live Organ Donation". During the discussion, there was unanimous agreement that live organ donation was not cost neutral for the donor in any country. Not only did the donation cost an organ (or part thereof), it usually cost some sum of monies from lost wages and out-of-pocket expenses. In this forum, the international community felt that we should do better.

In fact, if we can create a model that minimizes the personal cost to the live organ donor (family), we are likely to see more donors from people at the lower end of the financial spectrum step forward to donate for the benefit of their loved ones. An important point of this goal is that the projected cost of making organ donation cost neutral would not be more than the savings to the system, as it costs more to keep someone on dialysis than to transplant them.

The major areas to be addressed should include:

1) Health Insurance/Automatic Medicare eligibility in the event that the organ donor develops a medical condition requiring treatment as a consequence of the donation.

2) Short term disability and life insurance to benefit the families of donors who either die or are unable to return to work after donation.

3) Reimbursement for out-of-pocket expenses. A variety of methods could accomplish this end, but most would require authorization to assign these costs to the Medicare cost center at the transplant center.

The financial benefits of transplantation to our society are real. The media are fond of stating that there are not enough organs available in the U.S. and that people from this country are traveling overseas to obtain organs. Within all ethical means, we need to increase the organ availability for those who would benefit from organ transplantation. Yes, we need to continue to develop new methods and systems that increase the numbers of organs from deceased donors. But a simple look at our live donation system reveals that presently, we penalize the person who wants to donate an organ. As a society, we can and should be able to do better. The savings to the system by removing more people from dialysis makes the continuation of financial disincentives to live organ donation absolutely inexplicable.