



“Improving Human Life by Advancing the Field of Transplantation”

AST – ACOT open letter

The American Society of Transplantation is an organization of transplant professionals; physicians, surgeons, scientists, pharmacists, social workers, and others whose mission is to improve the lives of people with organ failure.

It is accepted that living donor kidney transplantation saves lives, often providing the very best possible outcome for the recipient. As advancements in the surgical technique have reduced the operative and perioperative risks to an absolute minimum, more family members, friends and acquaintances have come forward to help their loved ones. The AST believes that the cornerstone of safe living donor kidney transplantation is the education of donor and recipient about the risks and benefits of living donor kidney transplantation. Additionally, the AST is concerned there is inadequate education about living donor kidney transplantation and this lack of education creates a barrier in access to living donor kidney transplantation for individuals in disadvantaged socio-economic classes and more remote parts of the country. Finally, the AST believes it is the responsibility of the transplant community and the governmental agencies overseeing transplantation to work to eliminate barriers in access to living donor transplantation for all members of society regardless of income, education or place of residence.

The growing disparity between the number of patients in need of transplantation and availability of transplantable organs has increased interest in living kidney donation. This increased interest has resulted in individuals coming forward to be evaluated for kidney donation who do not fit the classical definition of a kidney donor. The term used to describe this type of donor is “the medically complex donor”. Such individuals may have pre-hypertension or overt hypertension, early glucose intolerance or mild obesity. While a paternalistic approach to evaluating these donors would be to decline them out of hand, it is becoming recognized that their opinions should be accounted for in the donor evaluation process. After all these individuals love and care for their potential recipient with the same intensity as a “medically perfect donor” and have a right to assume risk to help someone they care about. However it is here that the AST is concerned. There exists an incomplete understanding of live donor outcomes and by allowing the medically complex donor to donate without the necessary information to evaluate the risk, we may be in breach of our fiduciary responsibility to them. Despite the long history of living organ donation, the information regarding medical and psychosocial consequences is lacking. Moreover, the information that does exist, while helpful, reflects only short-term outcomes which are not relevant for a donor who will live out a lifetime and wishes to understand the long-term implications and risks associated with their decision to donate. The AST recognizes that clinical experience informs us that living donation is fundamentally safe in both the short and long term and therefore does not believe that the current deficiency in understanding the long term outcomes of kidney donation should limit the existing practice. However the AST strongly believes

that the best way to honor these remarkable individuals as well as continue to improve transplantation is to begin to study the question of long-term donor outcomes now.

The AST wishes to emphasize the following concerns and provide recommendations to address them.

- **There is an incomplete understanding of live kidney donor outcomes.** Despite the long history of living kidney donation, there is incomplete information regarding medical and psychosocial consequences. This limits the ability to counsel potential donors. Short-term follow-up is mandated by the OPTN at the center level, though many centers struggle with providing accurate data on all donors. Longer-term data is even more difficult to generate. At the current time, there is no widely available mechanism to fund donor follow up and data analysis.

AST endorses:

1. Developing approaches to obtain meaningful, long-term outcomes data that can be used to properly inform and educate potential living kidney donors about the risks of donation.
 2. That the above referenced outcome data be collected in a manner so that it can be used to educate a donor about their unique risk based upon their individual health characteristics.
 3. Targeted efforts by the OPTN and other interested parties to define parameters most likely to inform the living donor process, then collecting and analyzing data in a cost effective manner that does not pose undue burden on transplant centers or donors.
- **There are educational deficiencies about that availability and benefits of living kidney donation.** While there is a growing awareness of the benefits of living donation, there are regions of the country where the rate of living donation lags. While there may be justified reasons for this, the AST is concerned that there is also a lack of educational materials available to patients to assist them in the process of seeking referral for transplantation and understanding the option of living donor transplantation.

AST endorses:

1. Partnering with the Health Resources and Service Administration and other interested parties to develop and disseminate educational materials about the option of, the means to obtain, the associated risks and potential benefits of living kidney donation.
 2. Fully transparent education of the potential living donor regarding known risks and benefits of donor testing, surgery, and long-term outcomes.
- **There is no guarantee living kidney donors will have health insurance when it is needed.** Insurance coverage for the living kidney donor can become problematic in both the short- and long-term. The cost of the surgical procedure and the care following the surgery are generally covered by the recipient's insurance, but only for a defined, and relatively brief, period of time. More importantly, because data about health outcomes that reflects a time frame relevant to the healthy kidney donor is lacking, ensuring the availability of health insurance when the kidney donor is likely to need it provide an important safety net. The AST believe

ensuring the well-being of the living kidney donor is both a moral imperative and an acknowledgment of what the donor has done for the recipient and society as a whole.

The AST endorses:

1. Advocacy for access of living donors to health insurance.
2. Exploration of provision of insurance coverage for donors (such as Medicare eligibility) to assure protection from financial expenses that might arise as a consequence of donation.

The **American Society of Transplantation** believes that by addressing the issues outlined above, both the process and outcome of living organ donation in the United States can be improved. Furthermore, the AST believes that living kidney donation can be advanced in an ethical fashion with the necessary protection for potential living donors via the following additional measures:

- Educational programs to increase public awareness of the benefits of organ donation.
- Professional education programs addressing living donor issues and utilization.
- Promotion of kidney paired donation.
- Public recognition of organ donors and their families through Honors/Donor medals.

Presented By: Richard Formica, MD
On behalf of the AST Board of Directors