

Living Organ Donation

Living donor transplantation saves lives, often providing the very best possible outcome for the recipient. Utilization of organs from living donors is now an accepted practice for both kidney and liver transplantation.

Growing disparity between the number of patients in need of transplantation and availability of transplantable organs has increased interest in living donors. Innovative approaches have been developed to increase the numbers of living donors, including use of non-directed donors, paired donation, and immunologic conditioning of recipients to allow the successful transplantation between previously incompatible donor-recipient pairs. At the same time, there is increasing interest in the risks (medical, psychosocial, and financial) living donors accept to benefit others, and in ensuring appropriate protection (short- and long-term) for those who choose to donate. Critical issues include:

- Incomplete understanding of living donor outcomes. Despite the long history of living organ donation, there is incomplete information regarding medical, psychosocial, and financial 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. Fully transparent education of the potential living donor regarding known risks and benefits of donor testing, surgery, and long-term outcomes.
 - 2. 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.
- Non-reimbursed financial expenses incurred by donors. Many medically suitable and willing
 potential living donors are unable to donate due to financial disincentives. Potential donors are often
 saddled with many out-of-pocket expenses associated with the evaluation and donation (travel to the
 transplant center, subsistence, housing, and child care), as well as lost wages and some incurred
 medical expenses. Current mechanisms for reimbursement of expenses are clearly insufficient. The
 AST endorses:
 - 1. Financial neutrality for all living donors. In brief, living donation should be financially neutral; that is, living donors should not incur any out-of-pocket expenses to donate and all donation-related expenses should be reimbursed within the scope of federal law. Living donors restore health and well-being to transplant recipients and reduce societal healthcare costs for transplant candidates who otherwise would remain on the transplant waiting list and require continued care for end-stage organ failure. The AST strongly advocates for programs and policies that achieve financial neutrality, including reimbursement of travel expenses, lodging, lost wages, medical and pharmacy expenses related to donation, surgical complications, costs associated with regulatory follow-up visits, and other out-of-pocket expenses associated with living organ donation.
 - 2. Priority status for prior organ donors who subsequently develop end-stage organ failure and require transplantation.
- **Difficulty obtaining health and/or life insurance as a consequence of donation**. There is both empirical and anecdotal evidence indicating that some living organ donors experience difficulty obtaining affordable health or life insurance, or are reclassified at a higher actuarial risk for life insurance (with associated higher premiums) due specifically to their status as a living donor. The AST endorses:
 - 1. Advocacy for access of living donors to life and health insurance without adverse determination of risk status or higher annual premiums due solely to their status as a living organ donor.
 - 2. Legislation that would protect living organ donors from discrimination by health and life insurance companies based on their status as living donors.

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



- Educational programs to increase public awareness of the benefits of living organ donation.
- Professional education programs addressing living donor issues and utilization.
- Expansion of paired living donation.
- Public recognition and acknowledgement of living organ donors.

Approved by the AST Board of Directors on April 13, 2009
Revisions approved by the AST Board of Directors on September 6, 2011
Revisions approved by the AST Board of Directors on December 6, 2012
Revisions approved by the AST Board of Directors on June 25, 2013
Revisions approved by the AST Board of Directors on May 28, 2020

American Society of Transplantation (AST)

1120 Route 73, Suite 200 Mount Laurel, NJ 08054 Phone: (856) 439-9986 Fax: (856) 439-9982 Email: info@myAST.org

Website: www.myAST.org

Contact:

Shandie Covington, Executive Director, scovington@myast.org; 856-316-0924

Bill Applegate, Director of Government Relations, bill.applegate@bclplaw.com; 202-258-4989