

## A Roadmap for Removing Disincentives for Living Organ Donors

### Statement of Purpose

There is a growing disparity between the number of patients in need of transplantation and the availability of transplantable organs. Medically suitable and willing potential living donors are unable to donate due to financial disincentives, including costs associated with donation-related evaluation, transportation or travel, post-donation child or other dependent care, lost wages, and early and late medical expenses. Current reimbursement of actual expenses remains insufficient and overly complex. **While the American Society of Transplantation explores incentives for living donation, the AST urges policy changes to achieve at least financial neutrality in living organ donation and minimize non-financial donation-related burdens.**

### Key Definitions

- **Incentives:** Direct or indirect financial benefits provided beyond the costs of donation to encourage individuals to donate.
- **Disincentives:** Financial, social, or health-related burdens that discourage individuals from donating.
- **Financial Neutrality:** A principle that living donors should not be financially worse off nor have financial gain from donating.

### Three Priority Advocacy Areas for Action:

#### **Government Sector**

- **Expand Donor Medical Coverage**
  - Advocate for legislation requiring that commercial insurance cover essential donor evaluation procedures currently reimbursed by Medicare through Organ Acquisition (e.g., colonoscopies, mammograms, dental exams, OB/GYN visits).
- **Employer Support and Paid Leave**
  - Promote federal or state legislation incentivizing employers to provide paid leave specifically for organ donation, moving beyond reliance on unpaid FMLA.
- **Tax Incentive Reform**
  - Advocate for removal of income caps on existing state tax deduction/credit programs to ensure all donors can be reimbursed for costs such as travel, lodging, and lost income.
- **Private Insurance Parity**
  - The AST strongly supports the passage of the Living Donor Protection Act to prohibit insurance discrimination against living donors across the United States.
  - Push for regulations or incentives encouraging private insurers to adopt longitudinal post-donation protections like those currently available with Kidney Paired Donation (KPD) Registries, ensuring coverage and support for all donors.

#### **Public Sector**

- **Broaden covered expenses through National Living Donor Assistance Center (NLDAC) Eligibility**
  - Through the recently announced HHS commitments, remove the recipient's income cap and increase covered expenses to achieve financial neutrality.
- **Expand Donor Medical Coverage**
  - Petition CMS to standardize coverage for post donation care between traditional Medicare and Medicare Advantage plans.

- **Standardized and Simplify Resource Assessment and Access**
  - Through close collaboration with donors and donor families, implement policy requiring transplant programs to use standardized procedures for ensuring that prospective living donors are educated about and able to use the full range of financial and non-financial support resources available.
  - Implement policy requiring health insurers and regulators to minimize administrative burden and complexity for living donor covered services so that all eligible living donors may benefit.
  - Petition CMS to include in the CMS Medicare Conditions of Participation (COPs) a requirement for transplant programs to provide donor and family education on living donation and paired exchange as well as alternative treatment options.

### ***Private Sector***

- **Need for Ongoing Longitudinal Data and Study**
  - Support research and policy to gather data on long-term medical, psychosocial, and economic impact of living donation, as well as understanding barriers to living donation, to improve safety, decision-making, and consent processes, which are currently limited yet critical to identifying barriers and disincentives.
- **Employer Support and Paid Leave**
  - Recommend that transplant centers take a proactive role in encouraging employers to adopt Organ Donor Leave Policies by directly communicating or collaborating with a donor's employer (with the donor's permission) and recognizing participating employers through the AST Living Donor Circle of Excellence.

### ***Cross-Sector Coordination***

- **Expand Definition of Donation Costs and Burdens**
  - Work to adopt a broader understanding of donor burdens before and after donation- including direct costs for healthcare services and travel; indirect costs in the form of dependent care, lost wages, job insecurity, and healthcare access post-donation; and intangible costs, including emotional and quality of life impact.

### **Additional Steps**

In advocating for the elimination of disincentives to living donation, AST will examine, in parallel, the legal, ethical, and practical considerations involved in a pilot study of financial incentives for living organ donation.

#### **American Society of Transplantation (AST)**

1000 Atrium Way, Suite 400

Mount Laurel, NJ 08054

Phone: (856) 439-9986

Fax: (856) 439-9982

Email: [info@myAST.org](mailto:info@myAST.org)

Website: [www.myAST.org](http://www.myAST.org)

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