

Lived Experience, Real Impact: Donor Families and Recipients Share Insights About the Organ Donation System

First-hand accounts from donor families and transplant recipients illuminate the emotional realities, systemic gaps, and opportunities that data alone cannot capture—offering a vision for a sensitive and more effective organ donation system.

Purpose of Our Work

The Association of Organ Procurement Organizations (AOPO) leads the nation’s organ donation community with a clear mission: save more lives. Central to that mission is a commitment to continuous quality improvement—advancing donation and transplantation practices, collaborating with stakeholders, and sharing best practices across its network of organ procurement organization (OPO) members.

ECONOMETRICA, INC.

In March 2025, AOPO partnered with Econometrica to launch the OPO Performance Measurement project—bringing together 53 OPOs to develop independently validated, data-driven metrics that promote transparency, trust, and system-wide quality improvement.

Why OPOs Matter: A Family Donor Perspective

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Why OPOs Matter A Donor Family Perspective



Marie Bernard Johnson
and her husband Stephen

Integrating Key Perspectives

To build performance measures that truly matter, AOPO needed to go beyond operational data. The most important perspectives—the ones capable of revealing what’s working, what’s falling short, and what genuine improvement looks like—belong to the people who have lived through the experience of organ donation and transplantation.

Capturing those voices, and translating them into actionable insight, required a deliberate and person-centered approach.

How We Gathered Lived Experiences

Econometrica, on behalf of AOPO, conducted individual and small-group interviews with donor families and transplant recipients. These conversations explored personal experiences, perceptions of care and support, and insights that can guide improvements in OPO performance measurement and overall system effectiveness.

Three themes emerged consistently across interviews:

- ▶ **Emotional Experiences:** Capturing the emotional journey, decision-making processes, family dynamics, and interactions with healthcare providers.
- ▶ **System Perceptions:** Exploring trust, transparency, and fairness within OPOs, transplant centers, and the matching process.
- ▶ **Recommendations for Systemic Improvement:** Highlighting participants’ suggestions for enhancing communication, family support, and policy reforms.

For more information about this project please visit:

<http://www.aopo.org/opo-metrics-project/>.

What They Told Us

Emotional Experience

Donor families described donation discussions as emotionally taxing—often sudden, always profound. Yet most viewed it as the right choice: to honor a loved one's decision, or to give the gift of life to a stranger.

Transplant recipients, by contrast, recalled decisions made quickly and urgently, sustained by family support and trust in their care teams.

System Perception

Across both groups, interactions with OPOs were consistently praised for compassion and professionalism.

Challenges focused on communication gaps, including limited understanding of the matching process and why matches fail, inconsistent coordination among hospital providers, and broader public confusion about how the organ donation system works.

Recommendations for Systematic Improvement

Participants offered specific, actionable recommendations:

- ▶ **Communication and education.** Initiate donation discussions earlier, provide clearer information on how the waiting list operates and how matches are determined, replace clinical language with person-centered alternatives, and ensure OPO staff are trained to meet families where they are emotionally.
- ▶ **Family support.** Strengthen post-donation follow-up and aftercare programs to provide closure and emotional support for donor families and recipients.
- ▶ **Policy and system reform.** Extend Medicare coverage beyond 36 months for kidney transplant recipients, streamline donor registries, develop evidence-based protocols for donation timing, and ensure prescription cost transparency.

Most importantly, participants urged that lived experience be integrated into every committee and policy decision affecting organ donation and transplantation—not as a footnote, but as a foundation.

Donor Families Say:

Earlier, clearer conversations about donation would reduce the emotional burden of sudden decisions at the worst possible moment.



Transplant Recipients Say:

Post-transplant support and connection to donor families is essential—not optional—to long-term emotional recovery.



Key Takeaway

The lived experiences of donor families and transplant recipients underscore that a more compassionate, transparent, and person-centered organ donation system is both urgently needed and deeply achievable. Their stories highlight the emotional weight of donation decisions, the importance of clear and timely communication, and the value of ongoing support throughout the donation and transplantation journey—insights that should guide future improvements in practice, policy, and family care.

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