

Support for Transplant Caregivers

Understanding the HOLD Act

April 2026



At a Glance

What is the HOLD Act

The Honor Our Living Donors Act (H.R. 628 / S. 957), signed into federal law on February 6, 2026, corrects a long-standing inequity in how the federal government determines who qualifies for reimbursement of living organ donation expenses.

What the HOLD Act Does

1. Removes the Recipient Income Barrier

Ends the practice of considering recipient income when determining donor eligibility for NLDAC reimbursement. Before this law, if the recipient's income exceeded 350% of the federal poverty level (~\$55,000), the donor could lose access to reimbursement—even if the donor had limited means. Now, donors are no longer penalized based on the financial status of the person they are helping.

What does that mean for donors and caregivers:

More donor cases will qualify for NLDAC reimbursement, and when a donor qualifies, associated caregiver reimbursement—including travel, lodging, meals, and lost wages—tied to that case can proceed. Previously, entire cases could collapse if the recipient's income exceeded the threshold, leaving both donors and their family caregivers without support.

2. Requires Transparency and Accountability

- The Secretary of Health and Human Services must submit an annual public report to Congress detailing whether funding was sufficient to reimburse all eligible donors.
- The report must estimate the amount required to fully fund the program.
- This creates a pathway for future expansion and ensures Congress has the data needed to act.



The Transplant Caregiving Crisis

Last year, over 49,000 solid organs¹ and nearly 23,000² cell transplantations, were performed in the United States. Behind every transplant patient is at least one family caregiver who provides essential physical, emotional, logistical, and/or financial support throughout transplantation.

In fact, most transplant centers require patients to identify an available caregiver before they can even be placed on a transplant waitlist. Yet research from the National Alliance for Caregiving (NAC), through its [Transplant Caregiving Collaborative](#) reveals that transplant caregivers are unrecognized, unprepared, and under-resourced. Caregivers go uncompensated for their time, receiving limited support to care for the transplant patient, much less maintaining their own health and well-being.

The National Living Donor Assistance Center (NLDAC) reimburses donation related expenses, including support for caregivers. When the transplant center certifies medical necessity, NLDAC may cover caregiver travel, lodging, meals, and limited lost wages. Reimbursement requires supporting documentation, are capped at \$6,000, and depends on available program funds, factors that have historically limited access to this assistance.

The Financial Burden on Living Donors and Their Family Caregivers

Living organ donation is the gold standard treatment for patients with chronic kidney and liver disease, yet financial barriers prevent many potential donors from giving the gift of life. Donors and their caregivers face significant out-of-pocket costs including travel to transplant centers, lodging, lost wages, and childcare or eldercare expenses.

The NLDAC provides up to \$6,000 in reimbursement for living donors' travel, lost wages, and dependent care expenses, including travel for a support person or caregiver. However, until now, 91% of living donors were ineligible for this assistance because eligibility was based on the organ recipient's income, not the donor's own financial circumstances.

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A caregiver should not have to lose sleep over the possibility of losing their job because they need to take time off to help care for their transplant recipient. They should not have to worry that maintaining their transplant recipients' health and life will bankrupt them.

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- NAC, Transplant Caregiving in the U.S.: A Call for System Change



What Is the Honor Our Living Donors Act (HOLD Act)

The Honor Our Living Donors Act (H.R. 628 / S.957), signed into federal law on February 6, 2026, corrects a long-standing inequity in the federal reimbursement system for living organ donors. The law reforms how the NLDAC determines eligibility for reimbursement of donation-related expenses.

What the HOLD Act Does

The HOLD Act ends the practice of considering recipient income when determining donor eligibility. Donors are no longer penalized based on the financial status of the person they are helping.

Before this law, living donors could be denied reimbursement based not on their own financial situation, but on the income of the person they were helping. If the income of the person receiving the organ donation exceeded 350% of the federal poverty level (currently around \$55,000), the donor could lose access to reimbursement for lost wages, travel, lodging, and related expenses. This policy placed financial risk on donors who were already stepping forward to save a life.

The law also requires the Secretary of Health and Human Services to submit an annual public report to Congress detailing whether funding was sufficient to reimburse all eligible donors and estimating the amount required to fully fund the program. This adds transparency and accountability to the federal reimbursement system.

Although the HOLD Act does not create new categories of caregiver support, it makes a meaningful difference for caregivers by expanding donor's eligibility and strengthening the stability of existing assistance. By removing an unfair income-based barrier, the law ensures that more donors and the caregivers who support them can access reimbursements through NLDAC. This shift helps caregivers more reliably receive the support they need throughout transplantation.

Why this Matters for Caregivers

NAC's research found that transplant caregivers face mounting costs from travel, lodging, parking, lost work time, and post-transplant medication and lifestyle changes that can persist for years after surgery. The transplant process is especially burdensome for caregivers from socioeconomically disadvantaged communities, who have less access to health insurance, employer benefits, and flexible work schedules.

The HOLD Act is a key step toward addressing the financial barriers that [NAC's Transplant Caregiving in the U.S. report](#) identified as a key source of caregiver strain. By expanding eligibility for donor reimbursements, including support for caregivers' travel and lost wages, the law recognizes that the transplant system depends on family caregivers and that they deserve tangible support.

By removing recipient income from eligibility determinations, more donor cases will qualify for reimbursement. When a donor qualifies, associated caregiver reimbursement, including support for travel and lost wages, tied to that case can proceed. Previously, entire cases could collapse if the recipient's income exceeded the threshold, leaving both donors and caregivers without support.

Several barriers remain to truly support donors and family caregivers in transplantation. For example, caregiver reimbursement remains dependent on transplant center certification that a caregiver is medically necessary. Applications must be initiated through the transplant center, and documentation of expenses or lost wages must be provided. Funding availability and administrative processes still affect access.

Moreover, many donors and caregivers may be unaware that reimbursement exists. Transplant centers vary in how clearly they explain the process and how proactively they assist families. The application process can feel bureaucratic and complex. The new annual reporting requirement will help identify whether funding gaps persist, but appropriations still determine whether all eligible donors are fully reimbursed.

Still, the HOLD Act addresses only one piece of the puzzle. NAC continues to advocate for broader policy reforms including comprehensive paid family and medical leave, a dedicated caregiver coordinator on transplant teams, standardized caregiver screening, and financial protection that ensure no caregiver risks bankruptcy to help save a life.



ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

The [National Alliance for Caregiving](#) is a catalyst for change, transforming how the United States recognizes, supports, and values the 63 million family caregivers providing complex care. Through our nationally recognized caregiving research and advocacy, we drive policy, system, and culture change to elevate family caregivers as a national priority. We foster partnerships across aging, disability, healthcare, philanthropy, and the private sector with the goal of making family caregiving more sustainable, equitable, and dignified.

NAC's [Transplant Caregiving Collaborative](#) addresses the challenges faced by family caregivers supporting loved ones before, during, and after transplantation. It advances research on transplant caregiver experiences, uplifts their stories, and develops policy recommendations to strengthen support across the transplant journey.

Learn more at www.caregiving.org

ABOUT WAITLIST ZERO

Founded in 2014 by Josh Morrison and Thomas Kelly who donated their kidneys to strangers, [Waitlist Zero](#) works with organizations and individuals to end the kidney shortage that kills 10,000 waitlist Americans annually.

We mentor people who want to donate kidneys, give talks about kidney donation, unite with organizations who want to end the organ shortage, testify about the kidney crisis and join forces with all who want to save American lives from preventable kidney deaths. We have also support programs to encourage people to consider living liver donation.

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