FAMILIESUSA
THE VOICE FOR HEALTH CARE CONSUMERS

Testimony of Anthony Wright
Executive Director, Families USA

Before the U.S. Senate Committee on Health, Education, Labor, and Pensions (HELP)

"Examining the Future of the U.S. Organ Procurement and Transplantation Network"

December 11, 2025

FamiliesUSA.org
1225 New York Avenue, NW, Suite 800
Washington, DC 20005
main 202-628-3030 / fax 202-347-2417

Chair Cassidy and Ranking Member Sanders, thank you for holding this hearing to address the many issues in our nation's organ procurement system.

It is an honor to be with you this morning. My name is Anthony Wright, and I serve as the executive director of Families USA, the longtime national, non-partisan health care consumer advocacy organization. For almost 45 years, Families USA has been working to achieve our vision of a nation where the best health and health care are accessible and affordable to all.

We appreciate the Senate HELP Committee's commitment to investigating the challenges facing those that need organ transplants in this country, and we urge policymakers to continue to take action administratively and legislatively to improve access and affordability, efficiency, transparency and accountability, safety and ethics, and better equity and outcomes for these patients.

The Committee is right to focus on the serious, widespread, and systemic problems with the country's national transplant system, including the Organ Procurement and Transplantation Network (OPTN), the longstanding OPTN operations contractor - the United Network for Organ Sharing (UNOS) - and the specific practices employed by the network of Organ Procurement Organizations (OPOs). The failings of the current system are startling: In 2023 alone, 11,000 potentially life-saving organs were wasted despite the wishes of their donors.[1] All the while, over 100,000 seriously ill patients linger unnecessarily on transplant waitlists, often for years, reliant on expensive and unending medical treatments such as kidney dialysis. Over a dozen people a day in America die waiting for an organ transplant.[2] And there are rampant disparities in the system, particularly for Black Americans, as well as other inequities based on ethnicity, income, and insurance status.[3]

As consumer advocates, Families USA has supported bipartisan efforts to address these issues from Congress and from the Biden and Trump administrations. We previously expressed our concerns in October 2020 to then Secretary of Health and Human Services (HHS) Alex Azar, urging the department to issue what was at the time a pending rule to bring much-needed accountability and oversight to our nation's organ procurement and transplant system.[4] Since then, we have seen the unanimous passage of important bipartisan legislation, the *Securing the U.S. Organ Procurement and Transplantation Network Act*.[5] And just last year, the Centers for Medicare and Medicaid (CMS) put forward the Increasing Organ Transplant Access (IOTA) model to increase access to life-saving kidney transplants for patients living with end-stage renal disease.[6]

Despite these efforts, much more is needed to make the organ procurement system responsive and accountable to patients across America. This includes implementing the existing law to break up the OPTN monopoly which is still, two years after the law's passage, dominated by UNOS, into separate functions for greater accountability; removing conflicts of interest of industry in governance and financial self-dealing to ensure that taxpayer dollars are used for patient care and not for the enrichment of organ contractors and their executives; maximizing the oversight authority of the Health Resources and Services Administration (HRSA) and the Centers for Medicare and Medicaid Services (CMS) to terminate organ contracts and decertify organizations not meeting key standards; and otherwise addressing misaligned financial incentives in Medicare that contribute to the system's failings.

Also, any discussion focused on patients must include addressing the need for continuous coverage and containing their costs. Organ recipients require costly medical care before, during, and following donation. Without affordable, ongoing coverage, a patient could be vulnerable to

medicals bills costing thousands — and in some cases, millions — of dollars. It would be a failure to families if policymakers address reforms of the organ procurement system, only to leave them bankrupt, in severe medical debt and without access to the lifesaving immunosuppressants and other medication needed to continue to care for the organ they received. To do right by organ recipients and patients in general, this Committee must work to ensure families continue to have access to affordable health coverage. While Congress must confront specific issues with organ procurement from a variety of angles, including by exploring ways to hold OPTN contractors and OPOs more accountable, the gift of life provided by organ donors will be squandered if transplant recipients lose access to affordable health insurance.

In this vein, Congress must come together right now to extend – in their current form and without harmful changes – enhanced premium tax credits for the nearly 22 million Americans who rely on them to purchase comprehensive health coverage from the federal or state health insurance Marketplaces.[7] Open enrollment began on November 1, and now millions of Americans are logging in to re-enroll in coverage only to see their health insurance premiums skyrocketing for next year — more than doubling on average,[8] with people paying not just hundreds but thousands of dollars more. Many will not be able to afford to buy a plan at all: if Congress fails to act, roughly 4 million people are likely to lose coverage next year altogether.[9]

To address this crisis, policymakers must pursue policy solutions that provide direct and immediate relief from crushing health care costs to individuals, families, and small business owners. We also must enact policies that get at the misaligned financial incentives and abuses that are widespread in the health industry and also central to some of the failures evidenced by the organ procurement system.

Urgent Public and Policymaker Oversight of the OPTN Needed

Congressional hearings, widespread media reports, and whistleblower statements over the past few years have uncovered systemic failures and grossly negligent behaviors of both the OPTN, its main contractor UNOS, and also OPOs, the 55 local monopoly contractors tasked with recovering organs for transplant.[10] These stories—of rampant line skipping, safety violations, nonviable organs collected and discarded for fraudulent Medicare reimbursement, and unethical procurement from patients still alive—are harrowing and must be dealt with honestly and publicly. Anything less threatens the trust of the public, including the millions of people like me that volunteer to be an organ donor, and thus the viability of our organ procurement system.

Congressional investigations (including those led by Senate Finance from 2020-2025, House Oversight Democrats in 2020-2022, Energy and Commerce from 2024-2025, and Ways & Means Republicans in 2025) have shown significant fraud, waste, and abuse by many OPOs and a lack of action and oversight from the OPTN, which until 2024 shared its board with its sole contractor UNOS, a board that includes many OPOs. We support the effort to implement the 2023 law to break up the contract and the monopoly of UNOS and to find different partners for different functions. We also support efforts to ensure that the governance of the OPTN has better conflict-of-interest requirements, and that includes voices from patient, consumer and community groups, rather than the industry they are supposed to oversee.

We are encouraged by HHS' initial efforts to hold bad actors accountable, including the announcement that HHS will for the first time decertify an OPO.[11] However, reform cannot stop with one organization in South Florida. Stories of improper or botched organ procurement continue to mount, and all must be investigated and those responsible held liable.[12] We note that HRSA

oversees the national OPTN, and CMS is responsible for certifying and re-certifying OPOs. CMS has the authority to terminate an agreement with other OPOs that no longer meet the requirements for certification, just as it is finally doing with the Miami example, and should immediately move to decertify other dangerous OPOs in which there is documented rampant patient abuse.

As the stewards of taxpayer dollars, Congress must act as well. The HHS Inspector General stated that Medicare has reimbursed OPOs for unallowed expenses unrelated to patient care, and that the current OPO reimbursement structure incentivizes fraud, waste, and abuse, writing that '[t]hese concerns not only negatively affect the Medicare trust fund but also negatively affect people in need of organ transplants.'"[13] The current system is costing tax dollars, in addition to the even more troubling issue of putting patients' lives at risk. These issues raised by whistleblowers of greed exploiting misaligned financial incentives in the organ procurement system are extreme versions of a story we recognize throughout the health care system. Monopoly power without oversight often increases costs to taxpayers and patients without providing better service or outcomes. We appreciate the leadership from Chair Cassidy, Ranking Members Sanders, and many members of this committee to rein in similar abuse of the health care system broadly—from reforming hospital pricing to Medicare Advantage improper payments like upcoding. Reforming the organ procurement system is another piece to that puzzle to ensure a health care system driven by patient outcomes and not insurance, hospital, or drug corporations' revenue and profit goals.

The Organ Transplant System Must Work Better for All Families

We support reforms to implement the enforceable and actionable metrics to address OPOs' failures that were finalized by both the Trump and Biden administrations, as OPO mismanagement amplifies underlying health disparities. We also support moves by HRSA to make OPO performance data publicly available, to ensure continuous oversight of the system by HRSA and CMS. We also support strong government action in investigating all patient safety concerns, rather than leaving this life-and-death responsibility with industry interests at the OPTN itself.

The evidence is clear. End-stage renal disease (ESRD) disproportionately affects Black Americans, Native Americans, Asian Americans and Americans of Hispanic origin compared to White Americans.[14] Despite Black Americans being three times more likely to suffer from kidney failure compared to their White counterparts, Black Americans are underrepresented on transplant waitlists.[15] Adding to these disparities, when Black patients do receive a kidney transplant, on average the transplanted kidney is of lower quality (presenting with a higher Kidney Donor Profile Index) than White patients.[16] Furthermore, the kidney transplant waitlist not only includes a higher number of White patients, but those patients also receive a disproportionate share of transplants.[17]

These troubling statistics actually understate the problem. Addressing issues related to the organ procurement and transplantation network would help those already on the waitlist—but broader barriers for the uninsured, low-income, and disadvantaged racial and ethnic groups prevent many who may need help from getting on the waitlist in the first place. Once on the waitlist, patients need HRSA and CMS to address the rampant line skipping and cherry picking of patients that has happened on the OPTN's watch. Ultimately, to authentically and meaningfully improve our nation's transplant system, we must confront these systemic issues and ensure fair and equitable access to transplant waitlists for all eligible patients, regardless of income, race, or ethnicity. That starts by ensuring that everyone maintains access to affordable health insurance.

Access to Insurance Critical for People with Chronic Illness and Organ Failure, as well as Organ Recipients

Affordable access to coverage is central to the conversation around a functioning organ donation system considering the medical costs associated with donating or receiving an organ can be astronomical.

The average reported cost of a solid organ transplant ranges from $260,000 for a single kidney transplant to over $1.2 million for combined heart and lung transplants.[18] According to the American Transplant Foundation, the average pancreas transplant can cost $408,800; while a heart transplant can reach up to $1.6 million in billed charges.[19] This doesn't include additional costs such as lifetime medication adherence to ensure the body doesn't reject the transplant, maintenance of the transplant, or potential complications. The National Institutes of Health (NIH) estimated long term oral maintenance immunosuppression and other prescription medications can cost patients upwards of $2,500 per month depending on various factors including the number of prescription medications and insurance coverage, with the average annual cost of medications between $10,000 and $14,000 per patient.[20] In kidney transplant recipients, loss of Medicare coverage (patients lose Medicare coverage 36 months after kidney transplant if their eligibility was tied to end-stage renal disease) results in reduced immunosuppressant adherence and increased organ rejection.[21]

The financial burden these procedures create requires that we ensure patients have access to robust and continuous coverage. Without proper coverage, any one of these costs would be enough to bankrupt a family or disrupt ongoing care that would cause the organ to fail.

In fact, coverage matters for patients to be listed for transplant in the first place: Americans who lose coverage may have greater difficulty being listed for transplants.[22] Transplant providers set their own policies for allocations of organs and consider health coverage as one of the medical and nonmedical factors in evaluating candidates for transplantation. OPTN's guidelines point to adherence as one such nonmedical factor, given that adherence to medical regimes post-transplant "increases the likelihood of a successful transplant." Adherence to taking immunosuppressants and other medications, going to regular follow-up and specialist visits, and other testing is heavily influenced by financial barriers and coverage. Potential recipients have been restricted from transplants because of lack of coverage, lapses in insurance, or shaky finances, which can also be a result of lack of coverage.

Yet we are at a crossroads in terms of health insurance in this country. We started 2025 with record low numbers of families who were uninsured--thanks to changes made through the Affordable Care Act (ACA) and the enhanced premium tax credits, we have seen a decrease in uninsurance rates for all age groups, different races and ethnicities,[23] and across income levels. Insurance expansions helped patients needing organ transplants: One study found that Medicaid-insured waitlist registrations and deceased donor transplants increased in states with Medicaid expansion, suggesting that Medicaid coverage improves access to transplants for low-income individuals.[24] Other studies have found increases in listings of people in need of organ transplant in Medicaid expansion states, including for livers and hearts.[25]

Unfortunately, we may expect to see a dramatic drop in coverage for nearly 15 million Americans, a combined effect of recent cuts to Medicaid and Congress' failure to extend enhanced tax credits for those who buy coverage as individuals.[26] This massive loss in insurance will undermine preventive

and primary care for millions and mean more people end up needing organ transplants, while making it harder for them to get that lifesaving care.

Congress Must Act Now to Pass a Clean Extension of Health Care Tax Credits

Given this, if this Congress wants to do right by current and future organ transplant patients, the most pressing priority right now is to extend the expiring enhanced premium tax credits to prevent a major premium spike and also prevent four million Americans from being pushed and priced out of coverage altogether. Despite Congress having several opportunities over the last year to extend these premium supports, including in a budget bill where other tax breaks were extended, no fix for families has moved forward. Now, in the midst of open enrollment, millions of families find themselves either being forced to try to secure health insurance with premiums that are double or triple their current amount or going without *any* health care coverage purely due to the cost.

The scale of this problem is significant: 22 million American workers who don't get coverage on-the-job or through Medicaid or Medicare qualify for premium tax credits for a plan through healthcare.gov or a state marketplace. That means their current household income is at least $15,060 for an individual or $31,200 for a family of four, and they do not have other options for affordable health coverage.[27] These tax credits are a lifeline for workers and their families, including those with serious and chronic health conditions like diabetes, heart disease, and cancer who need access to regular care to stay healthy and keep working when they don't get insurance through their job.[28] The average income of an organ transplant patient is around $68,000 per year--someone who if they bought their coverage as an individual would lose all affordability assistance if the enhanced tax credits expire.

The numbers are compelling, but so are the stories of the real people who rely on premium tax credits for their health and financial wellbeing. The enhanced premium tax credits have been lifechanging for people like Claire, a 43-year-old small business owner in Lafayette, Louisiana, who has been self-employed for her entire career. Diagnosed with breast cancer at 27, she relies on the Affordable Care Act's premium tax credits to afford the ongoing care she needs to stay healthy. Living with a preexisting condition that requires comprehensive care, she said she could never be well-served by the kind of short-term "junk plans" often misleadingly marketed as ideal for young adults. Thanks to the enhanced premium tax credits, she is able to secure the comprehensive insurance she needs through the health care marketplace. She now pays about $117 per month for her plan after tax credits — compared to the $570 that she would pay without them — allowing her to maintain her coverage for frequent screenings and biannual oncology visits. "My appointments are really important to not only my physical health but my mental health," she said. Losing those credits, losing access to her trusted physicians, or being forced into a cheaper plan with higher out-of-pocket costs worries her deeply. "Not being able to afford to go to the doctor is a reason that a lot of people don't go," she shared.[29]

Claire needs Congress to take immediate action, and she is not alone: Roughly three-quarters of Americans polled from across the country — and across party lines — want Congress to act to extend the enhanced credits.[30]

And since Congress failed to act to extend the health care tax credits before Marketplace Open Enrollment began, it is critical to both cleanly extend the tax credits without delay *and* to ensure people who have already decided they cannot afford to keep their coverage have the opportunity and assistance to come back and re-enroll.

We recommend that Congress also:

- Extend the current open enrollment period or authorize a Special Enrollment Period (SEP) to allow time for the new rates to be adjusted and for enrollees to see and shop for a plan that best meets their needs.
- Restore $90 million in funding for Affordable Care Act (ACA) Navigators to help ease confusion among enrollees. Given the confusion about coverage, with 1.5 million Americans projected to drop coverage just from the sticker shock, we need to restore the funding cut earlier this year to provide trusted outreach and free assistance to people shopping on the federal marketplace for health coverage.[31]

While Congress considers proposals related to the enhanced tax credits, it should recognize at this late date that it is logistically improbable – if not impossible - to make changes to the current tax credit structure or advance anything other than a clean extension for 2026. In addition, some of the proposals being talked about would be particularly problematic for organ transplant patients.

- Proposals to put $1,000 or $2,000 into a Health Savings Account would be a poor substitute for most people who now get the enhanced tax credit, especially given the base cost of coverage in general—but would be especially tough for an organ transplant patient facing a high deductible. Organ transplant patients can have on average out-of-pocket costs of over $4,000 per month just for medication.[32]
- Efforts that further move people to bronze or catastrophic plans with high deductibles of $7,500 or more may save on monthly premiums in a way that benefits healthy people who don't regularly access care, but be particularly burdensome to organ transplant patients that have significant medical needs in both prescriptions and medical visits, and thus would bear high out-of-pocket costs.
- Proposals to encourage people to purchase short term or junk coverage that does not have to abide by the ACA patient protections, would be a nonstarter for an organ transplant patient, who would likely be denied or discriminated against due to pre-existing conditions, or face even higher financial burdens if there was no annual or lifetime cap on out of pocket costs.

To further elaborate on this point, we highlight the story of Paul Gibbs from West Valley City, Utah, who was born with a serious medical condition in both kidneys. As an adult, he was told he needed a kidney transplant but was uninsured. Eventually, and after years of back and forth with insurance companies, Medicaid and Medicare, Paul was able to get his transplant covered by Medicare and Medicaid. Now as a transplant recipient, Paul must take medications every day for the rest of his life in order to keep his body from rejecting the donated kidney. Medication that he can't afford to pay for out of pocket, meaning that he has to stay covered and needs constant continuation of coverage for the rest of his life. Thankfully, after the ACA passed, consumer protections allowed him to get on his wife's employer-sponsored coverage. Paul's story shows how important continuous coverage that puts people first is for organ transplant recipients.[33]

Families Need Solutions Now

The urgency couldn't be clearer. Patients who need organ transplants need strong administrative and legislative actions to give them the best chance to lead healthy and financially secure lives. They need to have the security of continuous coverage, with access and affordability for medications and services—whether through work, Medicare, Medicaid, the marketplaces—

including with the extension of enhanced tax credits. They need regular primary and chronic care management to maintain their condition and slow the progression of disease, preventing or at least delaying the need for transplant. They need an organ procurement system that is efficient, ethical, and equitable. They need reforms for the organ transplant system and the whole health system that introduce more transparency and accountability and address the misguided financial incentives.

Such a system would not only save lives, but also save money, at a time when Americans are demanding relief from rising health care costs. For example, the faster we connect patients in need with a high quality and viable kidney, the less Medicare or private health care premiums have to pay for expensive dialysis—the cost to Medicare for patients on dialysis is over $45 billion a year, which equates to about $90,000 per patient per year, while expenditures for kidney transplant recipients in the year following their transplant are significantly less at only $23,308 per person, per year.[34,35]

Members of Congress from every state and district have a role to play in discussing and advancing commonsense legislation that would remedy some of the most obvious health system failings that drive unaffordable care, and the American people are eager to see action. **A recent poll from Families USA and Hart Research Associates shows that lowering health care costs is the top priority for Americans across demographics, even surpassing concerns related to housing, jobs, crime, and immigration.** Over 9 in 10 voters think it is important that Congress and the President act to lower health care costs to reduce stress on family budgets, bring down the cost of living, and to make health care more affordable and accessible to millions of families around the country.[36]

Thank you again for holding this timely and critical hearing. The journey to fully transform our health care system so that it truly works for American families is long, but Congress holds the power to take the next critical steps. Families USA stands ready to support you in this essential and urgently needed work.

---

[1] Steve Miller, "Addressing the Critical Challenge of Organ Non-Utilization," Association of Organ Procurement Organizations, March 27, 2024. https://aopo.org/donation-perspectives/addressing-the-critical-challenge-of-organ-non-utilization/

[2] Health Resources & Services Administration, "Organ Donation Statistics," May 2025. https://www.organdonor.gov/learn/organ-donation-statistics

[3] Kenneth W. Kizer, Rebecca A. English, Meredith Hackmann, et al., "Realizing the Promise of Equity in the Organ Transplant System," The National Academies Press, 2022. https://www.nationalacademies.org/read/26364/chapter/1#xi

[4] Families USA, "Letter Urging Improvements To the U.S. Organ Procurement and Transplant System To Better Support Families And Save Lives," October 30, 2020. https://www.familiesusa.org/resources/letter-urging-improvements-to-the-u-s-organ-procurement-and-transplant-system-to-better-support-families-and-save-lives/

[5] H.R. 2544- Securing the U.S. Organ Procurement and Transplant Network Act, September 22, 2023. https://www.congress.gov/bill/118th-congress/house-bill/2544/text

[6] U.S. Centers for Medicare & Medicaid Services, "IOTA (Increasing Organ Transplant Access) Model," September 30, 2025. https://www.cms.gov/priorities/innovation/innovation-models/iota

[7] U.S. Centers for Medicare & Medicaid Services, "2025 Marketplace Open Enrollment Period Public Use Files," May 12, 2025. https://www.cms.gov/data-research/statistics-trends-reports/marketplace-products/2025marketplace-open-enrollment-period-public-use-files

[8] Andrew Sprung, "Trump administration takes one more whack at the ACA marketplace." Xpostfactoid, September 4, 2025. https://xpostfactoid.substack.com/p/trump-administration-takes-one-more

[9] Congressional Budget Office, "The Effects of Not Extending the Expanded Premium Tax Credits for the Number of Uninsured People and the Growth in Premiums," December 4, 2024. https://www.cbo.gov/system/files/202412/59230-ARPA.pdf.

[10] Peter Whoriskey, "Whistleblower says U.S. organ transplants corrupted by greed and bias," Washington Post, September 17, 2025. https://www.washingtonpost.com/health/2025/09/17/kidney-transplant-organs-waiting-list/

[11] U.S. Department of Health and Human Services, "HHS to Close University of Miami's Failing Organ Agency," September 18, 2025. https://www.hhs.gov/press-room/hhs-decertifies-miami-organ-agency-reforms-transplant-system.html
[12] Brian M. Rosenthal, "U.S. Government Cracks Down on Organ Transplant System," The New York Times, August 28, 2025. https://www.nytimes.com/2025/08/28/us/federal-crackdown-organ-donations.html
[13] Office of the Inspector General, "Medicare Paid Independent Organ Procurement Organizations Over Half A Million Dollars For Professional and Public Education Overhead Costs That Did Not Meet Medicare Requirements," Department of Health and Human Services, August 2023. https://oig.hhs.gov/reports/all/2023/medicare-paid-independent-organ-procurement-organizations-over-half-a-million-dollars-for-professional-and-public-education-overhead-costs-that-did-not-meet-medicare-requirements/
[14] American Kidney Fund, "Addressing health disparities and advancing health equity," n.d. https://www.kidneyfund.org/government-affairs-advocacy/our-2023-policy-priorities/addressing-health-disparities-and-advancing-health-equity
[15] Jade Buford, Samantha Retzloff, Adam Wilk, et al., "Race, Age, and Kidney Transplant Waitlisting Among Patients Receiving Incident Dialysis in the United States," National Kidney Foundation, October 2023. https://doi.org/10.1016/j.xkme.2023.100706
[16] Nour W. Asfour, Kevin C. Zhang, Jessica Lu, et al., "Association of Race and Ethnicity With High Longevity Deceased Donor Kidney Transplantation Under the US Kidney Allocation System," American Journal of Kidney Disease, April 16th, 2024. https://pubmed.ncbi.nlm.nih.gov/38636649/
[17] Kristina Fritz et al., "United Network for Organ Sharing Database Analysis of Factors Associated with Kidney Transplant Time on Waiting List," Cureus, February 6, 2023. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9997046/; See also, Christine Park, Mandisa-Maia Jones, Samantha Kaplan, et al., "A scoping review of inequities in access to organ transplant in the United States," International Journal for Equity in Health, February 12, 2022. https://pubmed.ncbi.nlm.nih.gov/35151327/.
[18] T. Scott Bentley and Steven G. Hanson, "2011 US Organ and tissue transplant cost estimates and discussion." April 2011. https://us.milliman.com/en/insight/2011-us-organ-and-tissue-transplant-cost-estimates-and-discussion
[19] American Transplant Foundation, "Affording Organ Transplant and Help if You're Uninsured" n.d. https://www.americantransplantfoundation.org/affording-organ-transplant/
[20] Bertram L. Kasiske, David Cohen, Michael R. Lucey, et al., "Payment for Immunosuppression after Organ Transplantation. American Society of Transplantation." JAMA : The Journal of the American Medical Association 283, no. 18 (2000): 2445. https://doi.org/10.1001/jama.283.18.2445.
[21] Garcia Valencia et al., "Health Insurance and Kidney Transplantation Outcomes in the United States: A Systematic Review and AI-Driven Analysis of Disparities in Access and Survival." Renal Failure 47, no. 1 (2025): 2513007. https://doi.org/10.1080/0886022X.2025.2513007.
[22] Andrew A. Herring et al., "Insurance Status of U.S. Organ Donors and Transplant Recipients: The Uninsured Give, but Rarely Receive," International Journal of Health Services 38 (4) (2008): 641–652, available at https://www.researchgate.net/publication/23650191_Insurance_Status_of_US_Organ_Donors_and_Transplant_Recipients_The_Uninsured_Give _but_Rarely_Receive; See also, J.T. Thibodeau et al., "Health Insurance as a Requirement to Undergo Cardiac Transplantation: A National Survey of Transplant Program Practices," Transplantation Proceedings 45 (1) (2013): 360–363, available at https://www.sciencedirect.com/science/article/abs/pii/S0041134512006628?via%3Dihub; Francis D. Pagani, "Insurance Coverage and Heart Transplant Outcomes," Circulation: Cardiovascular Quality and Outcomes 9 (5) (2016), available at https://www.ahajournals.org/doi/10.1161/CIRCOUTCOMES.116.003209.; Emily Gee, "Testimony Before the house Ways and Means Oversight Subcommittee Hearing on Organ Procurement Organizations," December 2, 2025. https://waysandmeans.house.gov/wp-content/uploads/2025/11/Emily-Gee-Testimony-12.2.25.pdf.
[23] Thomas C. Buchmueller et al., "Effect of the Affordable Care Act on Racial and Ethnic Disparities in Health Insurance Coverage," August 2016. American Journal of Public Health 106 (8) (2016): 1416–1421, available at https://www.russellsage.org/sites/default/files/ajph.2016.303155.pdf.
[24] Bethany Lemont, "The Impact of Medicaid Expansion and Travel Distance on Access to Transplantation," Journal of Health Economics 94 (2024): Article 102858, available at https://www.sciencedirect.com/science/article/pii/S0167629624000031?ref=pdf_download&fr=RR-2&rr=9a2dbecc2a5ee5c1#sec6.
[25] Nabeel Wahid et al., "Affordable Care Act Medicaid Expansion Associated With Increased Liver Transplant Waitlist Access Without Worsening Mortality," Liver Transplantation 30 (1) (2024): 20–29, available at https://pubmed.ncbi.nlm.nih.gov/37486623; See also, Guilherme H. Oliveira and others, "Implementation of the Affordable Care Act and Solid-Organ Transplantation Listings in the United States,"JAMA Cardiology 1 (6) (2016): 737–738, available at https://jamanetwork.com/journals/jamacardiology/fullarticle/2540545.
[26] Center on Budget and Policy Priorities, "By The Numbers: Harmful Republican Megabill Will Take Health Coverage Away From Millions of People and Raise Families' Costs," August 27, 2025. https://www.cbpp.org/research/health/by-the-numbers-harmful-republican-megabill-will-take-health-coverage-away-from

[27] U.S. Centers for Medicare & Medicaid Services, “Advance premium tax credit (APTC),” n.d. https://www.healthcare.gov/glossary/advanced-premium-tax-credit/ ; U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. ”2024 federal poverty guidelines”, The minimum income limits are slightly higher in Alaska and Hawaii due to those states’ poverty guidelines. The income limits will increase slightly for 2026 - people may qualify then if their incomes their incomes are above 2025 federal poverty guidelines, listed here: https://aspe.hhs.gov/sites/default/files/documents/ dd73d4f00d8a819d10b2fdb70d254f7b/detailed-guidelines-2025.pdf

[28] Cheryl Fish-Parcham, “Health Premiums To Spike for American Workers and Small Business Owners If Enhanced Health Care Tax Credits Are Not Made Permanent.” Families USA. November 2025. https://familiesusa.org/wp-content/uploads/2025/10/National-ImportancePremiumTaxCredits-FactSheet_October-2025-Update.pdf

[29] Families USA, “Health Premiums To Spike for Louisiana Workers and Small Business Owners If Enhanced Health Care Tax Credits Are Not Made Permanent.” November 2025. https://familiesusa.org/wp-content/uploads/2025/11/Louisiana-ImportancePremiumTaxCredits-FactSheet_November-2025-Update.pdf

[30] Families USA, “New Poll: Crushing Health Care Costs Top Priority for Voters” October 22, 2025. https://familiesusa.org/press-releases/new-poll-crushing-health-care-costs-top-priority-for-voters/

[31] U.S. Centers for Medicare & Medicaid Services, “CMS Announcement on Federal Navigator Program Funding.” February 14, 2025. https://www.cms.gov/newsroom/press-releases/cms-announcement-federal-navigator-program-funding

[32] ABC News. ” Organ transplants, but only for those who can afford them,” December, 2018. https://abcnews.go.com/Health/organ-transplants-afford/story?id=59631506

[33] Families USA, ”Paul Gibbs: Jumping Through Hoops for Treatment.” 2019. https://familiesusa.org/stories/paul-gibbs-utah/

[34] National Institute of Diabetes and Digestive and Kidney Diseases, ”United States Renal Data System 2024 Annual Data Report” 2025. https://usrds-adr.niddk.nih.gov/2024/end-stage-renal-disease/9-healthcare-expenditures-for-persons-with-esrd#:~:text=in%2Dcenter%20HD.-,Highlights,costs%20(Figure%209.1b).

[35] League RJ, Eliason P, McDevitt RC, Roberts JW, Wong H. Assessment of Spending for Patients Initiating Dialysis Care. JAMA Network Open. 2022;5(10):e2239131. doi:10.1001/jamanetworkopen.2022.39131

[36] Families USA, “New Poll: Crushing Health Care Costs Top Priority for Voters.” October 22, 2025, https://familiesusa.org/press-releases/new-poll-crushing-health-care-costs-top-priority-for-voters/