

*Health Coverage in the U.S.***Health Coverage for Kidney Transplants in the U.S.****Atul Agnihotri**

Chief Global Growth Officer, Alliance for Paired Kidney Donation (APKD), United States

**Atul Agnihotri**

Atul Agnihotri, a kidney recipient and former Fortune 500 global leader, has turned his personal journey of awaiting a transplant into a mission to help others facing similar challenges.

As the Chief Global Growth Officer for the **Alliance for Paired Kidney Donation (APKD)**, a globally renowned organization that manages an industry-leading kidney registry, Atul is working directly with government officials, policymakers, and transplant centers across over 14 countries to remove barriers to living kidney donation through ethical best practices and innovative programs and expanding Paired Kidney Exchange systems worldwide.

Recently, Atul facilitated a historical agreement between the State of Israel and the United Arab Emirates that led to a series of kidney transplants saving the lives of three women in the two countries and opening the door for more. This first ever exchange between Israel and an Arab state, is the outcome of months of behind the scenes work by the Alliance for Paired Kidney

Donation, the UAE Organ Donation and Transplant Committee and the Israel Center for Transplantation.

Atul also serves as the Chairman and Executive Director of **Kidneys for Communities**, spearheading the first nationwide 'Community-Directed Donation'™ model in the U.S. This innovative program taps into the power of community to significantly increase altruistic kidney donations, with successful initiatives already launched for **First Responders, Farmers & Ranchers, and Children**, in partnership with leading organizations in these sectors.

Access to health coverage for end-stage renal disease (ESRD) and kidney transplants is a lifeline for thousands of patients in the United States (U.S.). Fortunately, almost all patients in the U.S. have access to payment structures for dialysis, transplantation, and immunosuppressants utilizing a combination of private and government-funded mechanisms. Nonetheless, while the healthcare system provides substantial support, especially through federally provided Medicare, financial barriers still limit access to kidney transplantation. These barriers particularly affect living donors, whose contributions to saving lives remain underappreciated and under protected by the current US-based healthcare payment structures. This article delves into the current landscape of ESRD treatment financing in the U.S., the challenges living donors face, and the legislative efforts aimed at improving support for donors.

**The Current State of Health Coverage for Kidney Transplants in the U.S.**

With approximately 786,000 patients currently undergoing dialysis and around 90,000 awaiting a kidney transplant, ESRD poses a significant public health challenge in the U.S.<sup>(1)</sup> Kidney transplants account for 86% of all organ transplants in the country, with the average cost of about \$150,000 per procedure and annual post-operative care amounting to over \$30,000.<sup>(2)</sup> Dialysis itself costs approximately \$100,000 per patient annually for the patients on Medicare, while commercial insurance pays \$20,000-30,000 per month for dialysis and associated ESRD-related co-morbidity costs, making ESRD one of the most expensive chronic conditions to treat. Medicare alone spends more than \$35 billion annually, 7% of total Medicare spending, on the management of ESRD patients, even though these patients comprise only 1% of all Medicare patients.<sup>(3)</sup>

In terms of coverage, U.S. patients typically rely on either public insurance programs such as Medicare, Medicaid, TRICARE, and the Veteran's Administration, or private insurance through employers or the Affordable Care Act. Medicare provides coverage for individuals over 65 and those with disabilities, ALS, or ESRD,

making it a critical safety net for kidney transplant patients. The Medicare End Stage Renal Disease Program, signed into law by Richard Nixon in 1972, is one of the few disease-specific entitlement programs of the US government. For individuals with ESRD under 65, Medicare covers costs only after 33 months, during which private insurance serves as the primary payer. During this time, Medicare covers 80% of what private insurance does not pay, and the remaining 20% is borne by the patient. Once Medicare assumes primary responsibility, the roles switch with Medicare paying the first 80% of the cost and private insurance covering the remaining costs, while the patient continues to pay out of pocket costs (also called a "co-pay"). These out-of-pocket costs are capped annually so that the patient is not burdened extraordinarily, after which all the costs are borne by private insurance and/or Medicare.

Approximately 97% of both living and deceased donor kidney transplants in the U.S. are covered by a combination of Medicare (57%), Medicaid (8%), and commercial insurance (33%).

The long wait times for deceased donor transplants, typically - 5 years, mean that the majority - around 70% - of these transplants are covered by Medicare or Medicaid. In contrast, recipients of living donor kidney transplants experience significantly shorter wait times, so most of these transplants (55%) are covered by commercial insurance, though Medicare and Medicaid still account for 43% of coverage in these cases.

In January 2023, Medicare extended lifetime coverage of immunosuppressive drugs for kidney transplant recipients, whose transplants were covered by Medicare but could not secure alternate insurance support, removing the previous 36-month limit.

**Challenges for Living Donors**

Living donors are essential to the success of kidney transplants, providing better outcomes than deceased donor transplants and offering recipients the chance to avoid long waiting times. However, living donors often face financial burdens that are not fully covered



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by insurance. While recipient insurance typically covers the donor's surgery and immediate medical expenses, complications that arise more than 90 days after donation are covered by Medicare but may not be covered by private insurance. Transplant centers often negotiate with insurers or absorb these costs to protect donors from financial hardship.

Beyond the medical costs of the evaluation, surgery, hospitalization, and follow-up for living kidney donation covered by recipient's healthcare payer, donors face additional financial challenges that have been estimated to exceed \$4,000 per donation.<sup>(4,5)</sup> Unfortunately, living donors must still take time off of work and often incur lost wages, travel expenses, and child/elder care costs. Despite the altruism inherent in donation, these financial barriers can deter potential donors, exacerbating the ongoing organ shortage.

#### The Living Donor Protection Act and Donor Protection Programs

The proposed Living Donor Protection Act represents a crucial step toward addressing the financial and insurance challenges faced by living donors. Programs like the National Living Donor Assistance Center (NLDAC) provide financial support for donors with recipients

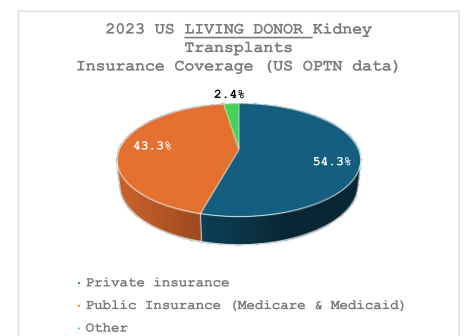
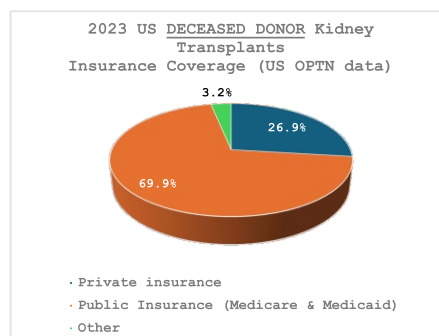
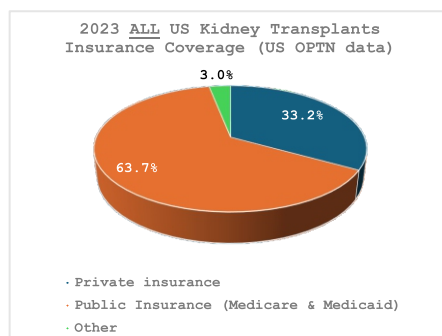
below the poverty line, and organizations like the Alliance for Paired Kidney Donation (APKD) and the National Kidney Registry (NKR) offer assistance for out-of-pocket costs to donors involved in paired exchanges.

#### Conclusion

While payment structures provide coverage for almost all US citizens with ESRD, challenges remain to overcome financial barriers that prevent some living kidney donations.

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#### Contributors



**Betty Crandall**  
APKD, Director, Transplant Center  
Administrative Relationships

Betty Crandall, MS, RN, is an experienced transplant administrator. During her nearly 30 years in the field of organ transplantation, Betty has worked with three transplant programs: The Johns Hopkins Comprehensive Transplant Center in Baltimore; Sentara Transplant Center in Norfolk, Virginia; and most recently, Wake Forest Baptist Medical Center in Winston-Salem, North Carolina. Additionally, she's assisted transplant programs throughout the country as an independent consultant or on a peer review committee and served on numerous committees for the United Network for Organ Sharing and the Organ Procurement and Transplantation Network. Currently, Betty helps APKD foster and build relationships with transplant centers across the United States.



**Prof. Michael A. Rees, MD, PhD**  
CEO, APKD

Together with his father, a computer programmer, Mike designed the first prototype of a computer program that matched willing but incompatible kidney donor and recipient pairs. Six years later, in 2006, he helped found the Alliance for Paired Kidney Donation, a globally renowned organization that manages an industry-leading kidney registry.

In addition to his role with the APKD, Mike serves as a professor in the Department of Urology, the Director of Renal Transplantation and transplant surgeon at the University of Toledo Medical Center.

Mike earned his medical degree from the University of Michigan then completed a three-year fellowship in transplantation at the University of Cambridge, where he completed research for a PhD in immunology.

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