March 20, 2025

Senator Shelley Moore Capito Chair Senate LHHS Appropriations Subcommittee 170 Russell Senate Office Building Washington, DC 20510

Senator Tammy Baldwin Ranking Member Senate LHHS Appropriations Subcommittee Hart Senate Office Building Washington, DC 20510 Representative Robert Aderholt Chair House LHHS Appropriations Subcommittee 272 Cannon House Office Building Washington, DC 20515

Representative Rosa DeLauro
Ranking Member
House LHHS Appropriations Subcommittee
2413 Rayburn House Office Building
Washington, DC 20515

Dear Chair Capito, Chair Aderholt, Ranking Member Baldwin, and Ranking Member DeLauro:

On behalf of the undersigned organizations representing patients and health professionals who receive and provide transplant care, we respectfully request that you continue to uphold Congress' commitment to our nation's organ procurement and transplantation system by including \$67 million for the Health Resources and Services Administration (HRSA) Health Systems Organ Transplantation program in the Fiscal Year (FY) 2026 Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations bill.

This investment would advance implementation of the bipartisan *Securing the U.S. OPTN Act* (P.L. 118-14) as well as support increased access to kidney transplantation, as outlined in President Trump's 2019 Executive Order on Advancing American Kidney Health (E.O. 13879). This legislation called for the first major Congressionally-directed reforms to the transplant system in decades, aiming to increase efficiency, transparency, accountability, and competition in the transplant network. To fulfill the promise of this historic law, increased investment for HRSA to modernize the system while maintaining service to the more than 100,000 Americans awaiting a transplant is essential.

The U.S. transplant system is the largest in the world and the number of transplants has increased annually—and yet major opportunities for improvement, as outlined in the Securing the U.S. OPTN Act, are both crucial and feasible. For example, many viable organs go unused (1 in 4 kidneys recovered for transplant are discarded despite evidence that many would have benefitted patients relative to dialysis). Owing in part to dated technology and lack of transparency, navigating the transplant system is notoriously difficult for patients and health professionals alike. A \$67 million Congressional investment is vital to the establishment of a modernized IT and data infrastructure to improve organ matching and tracking; to enabling increased transparency for patients; to ensure adequate staffing and expertise to guide multiple contractors through development and adoption the of next-generation technology; and to other advancements called for in Securing the U.S. OPTN Act.

Importantly, the requested \$67 million also encompasses support for HRSA's Living Organ Donor Reimbursement Program, which helps defray the cost of donating a kidney for socioeconomically disadvantaged Americans.

Lastly, clarification is needed that the HRSA and the U.S. Department of Health and Human Services have the authority to continue to collect and distribute OPTN patient waitlist registration fees to support the ongoing operation of the OPTN in appropriations bill text (as was recently clarified in statute).

HRSA has already taken several important steps towards implementation, such as shifting to a multi-vendor approach to contracting, separating contractor and OPTN boards, and launching the first transitional phase towards a modernized matching system that leverages industry-leading IT standards and practices. Continued Congressional oversight and a \$67 million in FY 2026 investment are imperative to guide, sustain, and expand this momentum—as well as to support living donors in giving the gift of life.

Our organizations thank you for your past attention to these issues and for your ongoing consideration of this respectful request for FY2026.

## Sincerely,

**Alport Syndrome Foundation** 

**American Kidney Fund** 

**American Nephrologists of Indian Origin** 

**American Nephrology Nurses Association** 

American Society of Diagnostic and Interventional Radiology

**American Society for Apheresis** 

**American Society of Nephrology** 

**American Society of Pediatric Nephrology** 

**Atlantic Dialysis Management Services** 

**Atypical HUS Foundation** 

**Children's Organ Transplant Association** 

**DaVita** 

**Dialysis Patient Citizens** 

**Fresenius Medical Care** 

**Kidney Care Council** 

**Kidney Care Partners** 

**Kidney Transplant Collaborative** 

**IGA Nephropathy Foundation** 

**National Kidney Foundation** 

**NephCure** 

**Nephrology Nurses Certification Commission** 

**Nonprofit Kidney Care Alliance** 

**Northwest Kidney Centers** 

The Oxalosis and Hyperoxaluria Foundation

**Polycystic Kidney Disease Foundation** 

**Renal Physicians Association** 

**Renal Support Network** 

The Rogosin Institute

**Transplant Recipients International Organization** 

**US Renal Care** 

The Vasculitis Foundation

Waitlist Zero