



MILKEN INSTITUTE
CENTER FOR STRATEGIC PHILANTHROPY

A Giving Smarter Guide To Accelerating Research Progress

GIVE SMARTER



An Executive Summary

KIDNEY FAILURE

\$30B

per year is spent by Medicare for kidney failure patient care.

300

people begin treatment for kidney failure every 24 hours in the U.S.

\$600M

in federal research funding accounts for less than 2% of care costs.

This Giving Smarter Guide is the culmination of a year-long effort to identify strategic philanthropic opportunities that can move the needle on unmet needs specific to kidney failure research and treatment.

Kidney failure is an irreversible disease in which the kidneys can no longer support life. To live, patients suffering from kidney failure must initiate treatment to replace kidney function through dialysis or kidney transplantation. According to the Centers for Disease Control and Prevention (CDC), more than 300 people begin treatment for kidney failure every 24 hours in the United States. The quality of life (QOL) for these patients is severely impacted because their lives are forever changed.

Approximately 17 percent of U.S. adults live with chronic kidney disease (CKD), the most common form of kidney disease characterized by a gradual loss in kidney function. Nearly 600,000 CKD patients have progressed to a state of kidney failure, the final stage of CKD. A person living with CKD may not be aware of the disease until it has progressed to the point of kidney failure. This lack of awareness is a major barrier with serious ramifications for patient health, research support, and cost.

The healthcare costs are staggering. In aggregate, Medicare spends about \$30 billion per year for kidney failure patient care—accounting for greater than 7 percent of Medicare fee-for-service spending. Aside from the economic burden, this disease takes an emotional toll on patients and families, as they navigate their new realities of a demanding dialysis treatment schedule, extreme resultant fatigue, as well as lost wages and high out-of-pocket costs.

Although the federal government provides nearly \$600 million in CKD/kidney failure research funding, it is less than 2 percent of care costs and woefully disproportionate to disease prevalence. The pharmaceutical industry has faced several drug development challenges, and there has never been a drug developed primarily for the prevention of kidney failure. Several barriers that plague the CKD/kidney failure field can be classified in the following categories:

- Lack of disease awareness and workforce challenges;
- Lack of innovation in transplantation and dialysis delivery; and,
- Limited disease understanding at the molecular level.

At the behest of the Citrone family, the Milken Institute Center for Strategic Philanthropy convened world-renowned kidney experts and stakeholders to identify transformative research and systems opportunities where philanthropy could accelerate progress in the CKD/kidney failure space. The primary opportunities are as follows:

1. Channeling private investment to [spearhead public awareness campaigns](#) would be the first step to raise the national profile of the disease state, encourage policy reform, and attract funding dollars for research and improved therapies—similar to the experience for other high-profile diseases.
2. Private giving can also transform the kidney disease and transplantation workforce by [endowing annual summits and creating a global network of faculty](#) to nurture the future generation of researchers and physician-scientists.
3. Philanthropic giving can move the needle on organ scarcity by funding innovative efforts to [expand access to transplantation, increase living kidney donation](#) rates, and strategically invest in [artificial kidney development](#).
4. The catalytic potential of philanthropy can foster a culture shift regarding kidney disease, whereby patients are better informed and encouraged to participate in [clinical trials](#).

This Guide was developed with the express purpose of empowering patients, supporters, and stakeholders to make strategic, informed decisions when directing their energy and philanthropic investments into research and development efforts aligned with their interests.

For more information visit philanthropy.milkeninstitute.org

