



February 16, 2018

The Honorable Catharine M. Young
Chair, Senate Finance Committee
428 Capitol
Albany, NY 12247

The Honorable Helene E. Weinstein
Chair, Assembly Ways and Means Committee
923 Legislative Office Building
Albany, NY 12248

Dear Chairs Young and Weinstein:

I am submitting the enclosed written testimony on behalf of the New York Center for Kidney Transplantation, Inc. (NYKidney) to be included in the record for the Joint Legislative Public Hearing on the 2018-2019 Executive Budget Proposal in the Health/Medicaid area.

NYKidney is a not-for-profit consortium of the kidney transplant hospitals in New York State, designed to address the needs of waitlisted patients and improve the quality of kidney transplantation.

Thank you for your review of this testimony and for your consideration.

Sincerely,

Samantha DeLair
Executive Director

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2018
NEW YORK STATE
BUDGET HEARING
Health/Medicaid

Written Submitted Testimony of
Samantha DeLair
Executive Director

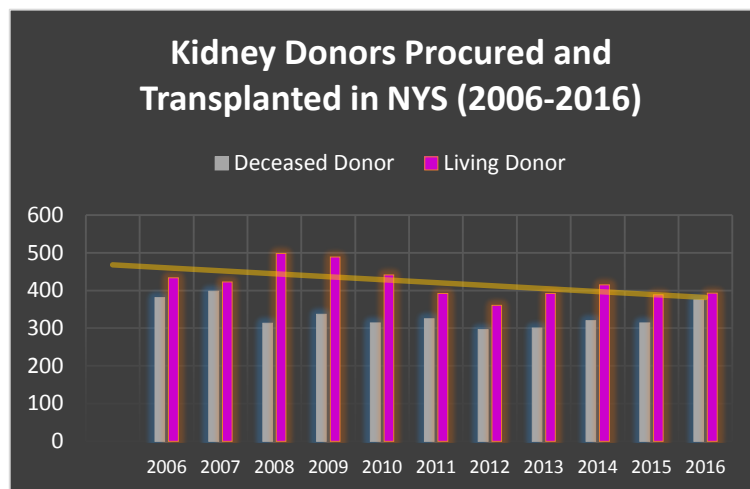
New York Center for Kidney Transplantation, Inc.
250 Jordan Rd
Troy, New York 12180



February 2018

The New York Center for Kidney Transplantation, Inc. (NYKidney) is a not-for-profit (NFP) organization comprised of the kidney transplant hospitals, organ procurement organizations and patient/public education groups in New York State (NYS); and is designed to address the needs of waitlisted patients and improve the quality of kidney transplantation. NYKidney is dedicated to increasing the number of kidney transplants and improving the outcomes of patients.

Currently, there are nearly 30,000 people on dialysis in NYS. There are 7,860 New Yorkers waiting for a kidney transplant; 1,430 have been waiting for over 5 years. In 2017, 1,048 donated kidneys were recovered from NYS donors and transplanted, half from living donors. Last year there were over 200 donated kidneys in NYS that were not used, some due to medical exclusions. Only 18% of the NYS waitlist was transplanted, while 617 New Yorkers died or were removed from the kidney waitlist because they were too sick to transplant; and 203 patients left NYS to be transplanted at another center. Despite increasing numbers of candidates on the waitlist; despite the knowledge that a successful transplant provides longer life and better quality of life than dialysis; and despite the fact that transplant reduces costs for the health care system; NYS kidney transplants have lagged behind the US for over a decade. In fact, 45% of NYS kidney transplants in 2017 were done using deceased donor organs imported from elsewhere in the country.



Additional efforts are needed to expand the supply of donated kidneys, and to use donated organs more effectively.

NYKidney's member hospitals have identified ways to increase the quality and number of kidney transplants, modeled after the activities of the state-funded liver consortium. We are appreciative of the State's investments in the long-term future of donation with the recently implemented changes to the NYS Donate Life Registry and are hopeful they will yield increases in donation over the coming decades, as registrants' donor designations are implemented at the time of their death. So as not to duplicate efforts, NYKidney initiatives target *current practice* to improve transplant through partnership with state, federal and mission-connected groups as follows:

Improve transplant program efficiencies in deceased and live donor efforts:

- **Participate in a pending international organ share pilot with Quebec Transplant;** a project partially supported by NYS liver, heart and lung transplant programs and through NYS legislative appropriations
- **Partner with NYS Organ Procurement Organizations** to perform statewide deceased donor utilization review to reduce the number of turndowns and discards of local and imported kidneys
- **Living Donor Support Act** reimbursement of lost wages will remove a disincentive to live kidney donation for vulnerable populations
- **Disparities Research** to determine existing differences in access to kidney transplantation and donation among minorities in NYS; identify disparities in referral rates from dialysis to transplant
- **Peer assist** – share best practices among transplant programs to improve performance

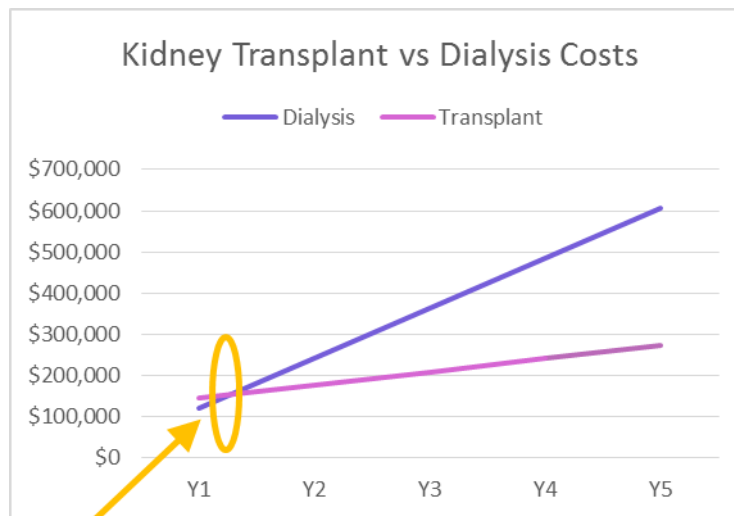
Professional and public education related to end-stage renal disease, kidney transplant and donation:

- **Shared resources for providers and patients** – consent and screening tools mandated at state and federal levels, financial education
- **Transplant Education for Patients with End Stage Renal Disease (ESRD):** develop culturally responsive education programs for patients with ESRD about the benefits of kidney transplant and options such as living donor transplant
- **Web-based, single point of entry education for non-directed live donors** - NYS regulations allow for non-directed living donation; such donors need education about living donation, its outcomes and kidney exchange options, to determine if they would like to pursue referral to a transplant center

Kidney Transplant vs Dialysis: Medicaid Savings

ESRD affects over half a million people in the US and the number of patients diagnosed with ESRD is increasing 5% each year. Patients with ESRD have two treatment options: dialysis or kidney transplant with a living or deceased donor. Many of the 30,000 New Yorkers on dialysis would benefit from kidney transplantation. After one year of treatment, those on dialysis have a 20-25% mortality rate, with a 5-year survival rate of 35% (USRDS, 2013). Patients who receive kidney transplants have over 90% survival rate after 5 years.

In addition to improvements in quality of life and survival, transplant also provides savings to the national Medicare system and to state Medicaid. According to the United States Renal Data System (USRDS, 2017), Medicare spending per patient in 2015 for hemodialysis was \$109,009 per year compared to \$44,092 for transplant; resulting in a 5-year savings of \$324,585 per transplanted patient.



The United Network for Organ Sharing, federal contractor that administers the national transplant waitlist reports primary payer data for all transplants in the US. Last year, 14% of NYS kidney transplants were done in patients with state Medicaid as primary payer, although most patients with ESRD should qualify for Medicare. A March 2017 report from the NYS Comptroller indicates the state is missing out on millions in Medicare payments for kidney patients. NYKidney has direct access to patients that will help target education efforts regarding eligibility for Medicare and help with the transition from Medicaid to Medicare.

New York State has had a rich history of collaboration with its organ transplant hospitals. In 1988, at the request of the NYS Department of Health, the liver transplant hospitals joined together to form a non-profit organization comprised of the seven liver transplant programs in NYS. In 2012, the NYS Transplant Council recommended the creation of a cardiothoracic transplant consortium (NYCTC) modeled after the work of the New York Center for Liver Transplantation (NYCLT). Over the past decade, the work of these organizations has been supported by aid to localities appropriations in the State budget and membership dues from the transplant programs. Currently, the organ transplant consortia receive \$477,000 in state funding; \$252,000 in Executive funding and \$225,000 in legislative adds.

We ask the Legislature to show its continued commitment to improving organ transplantation in NYS by providing \$450,000 in legislative appropriations in the 2018-2019 Budget to be used toward the initiatives of NYKidney. Given the savings of transplant over dialysis, we estimate an increase of less than 10 transplants will return the state's investment. Transitioning transplant patients from Medicaid to Medicare when possible will also provide additional savings to the system. However, NYS funding is critical to implement our agenda to improve the supply, quality and use of kidneys for the 7,860 New Yorkers on the waitlist.

Thank you for your consideration of these comments.