

February 11, 2020

The Honorable Liz Krueger Chair, Senate Finance Committee 172 State Street, Capitol Building Room 416 CAP Albany, NY 12247

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

Dear Chairs Krueger 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 2020-2021 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,

Carrie Lindower
Executive Director

Enc.

2020 NEW YORK STATE BUDGET HEARING Health/Medicaid

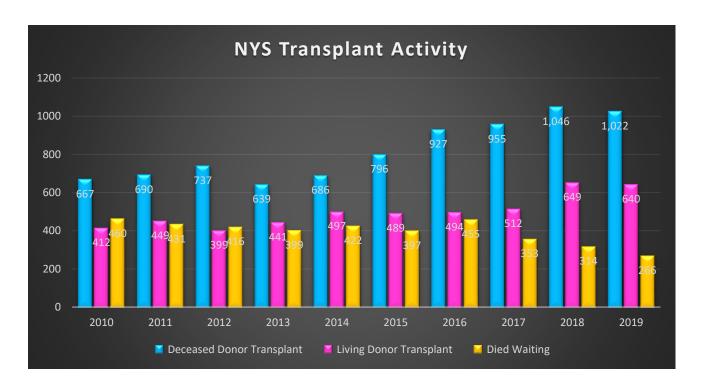
Written Submitted Testimony of
Carrie Lindower
Executive Director
New York Center for Kidney Transplantation, Inc.
PO Box 333
Lake Grove, New York 11755

February 2020

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 over 30,000 people on dialysis in NYS. There are 8,097 New Yorkers waiting for a kidney transplant; nearly 1,400 have been waiting for over 5 years. In 2019 less than 20% of the NYS waitlist was transplanted, while 522 New Yorkers died or were removed from the kidney waitlist because they were too sick to transplant; and 254 patients left NYS to be transplanted at another center. While we know that there are increasing numbers of candidates on the waitlist; that a successful transplant provides longer life and better quality of life than dialysis; and that transplant reduces costs for the health care system; we cannot meet the needs of our waitlisted patients in NYS. There are not enough organs available for transplant and our patients are dying while waiting.

Since its inception NYKidney has made a difference! The number of transplants has increased overall, living donor transplants have increased by 26%, the largest increase in the past 20 years. Death on the waiting list has decreased.



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 Anatomical Gift Act and are hopeful they will yield increases in donation in the future. 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 an international organ share pilot with Quebec Transplant; a project partially supported by NYS liver, heart and lung transplant programs and through prior 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 Protection Act: work with the NYS Department of Health to provide education about the living donation process.
- Living it Up NY Style: an in-person interactive workshop to help transplant candidates identify potential living donors
- Peer assist share best practices among transplant programs to improve performance

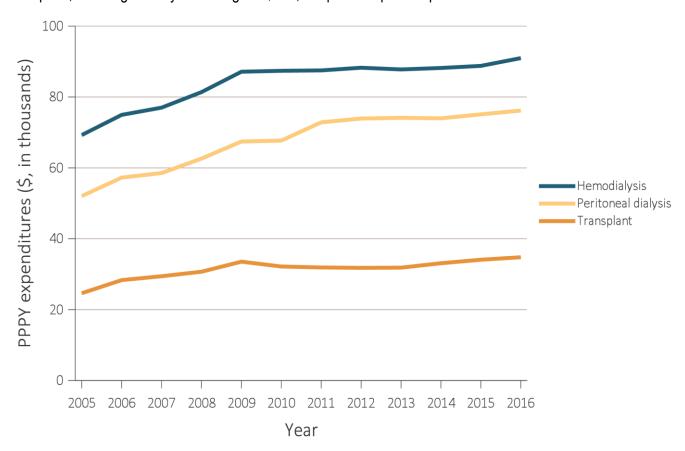
Professional and public education related to end-stage renal disease, kidney transplant and donation:

- Shared resources for providers and patients consent and screening tools mandated at state and federal levels, financial education
- Transplant Education for Dialysis Providers: (Project ECHO): innovative education
 partnership with dialysis centers statewide. Leveraging technology and the expertise of its
 transplant hospital members, NYKidney has created a virtual learning environment targeting
 dialysis providers to share knowledge, present best practices and improve communication
 between dialysis and transplant providers statewide
- 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 over 30,000 New Yorkers on dialysis would benefit from kidney transplantation. Per the 2018 Unites States Renal Data System (USRDS) annual report, the 5 year survival rate for patients on hemodialysis is 42%, compares to receiving a living donor transplant which has a five year survival rate of 84%.

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 2016 for hemodialysis was \$91,000 per year compared to \$35,000 for transplant, resulting in a 5-year savings of \$280,000 per transplanted patient.



Data Source: USRDS ESRD Database; Reference Tables K.7, K.8, & K.9. Period prevalent ESRD patients; includes all claims with Medicare as primary payer only. Abbreviations: ESRD, end-stage renal disease; PPPY, per person per year.

The United Network for Organ Sharing, federal contractor that administers the national transplant waitlist compiles primary payer data for all transplant candidates in the US. *Currently 21% of those waiting on the list in NYS have state Medicaid as their primary payer,* even though 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 eight 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.

We ask the Legislature to show its continued commitment to improving organ transplantation in NYS by restoring \$200,000 in legislative funding to the New York Center for Kidney Transplantation in the 2020-2021 Budget. 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 over 8,000 New Yorkers on the waitlist.

Thank you for your consideration of these comments.