

Living Donor Kidney Transplantation

A Failed American Enterprise

Who We Are

The Kidney Transplant Collaborative (“KTC”) is a national not-for profit focusing on kidney transplant with one goal: **to increase the number of kidney transplants in the United States faster.**

We are advancing this goal in two ways:

- **Research**: KTC developed a comprehensive grant program and invited hundreds of organizations to submit funding proposals for innovative ideas around organ transplant. To date KTC has awarded five grants and distributed \$3 million to further these proposals.
- **Advocacy**: KTC is advocating for policies to increase kidney transplants and reduce the financial and unnecessary barriers to transplantation for recipients, donors, and their families. Unlike others in the field, KTC is focused on increasing the number of living donor transplants in the United States.

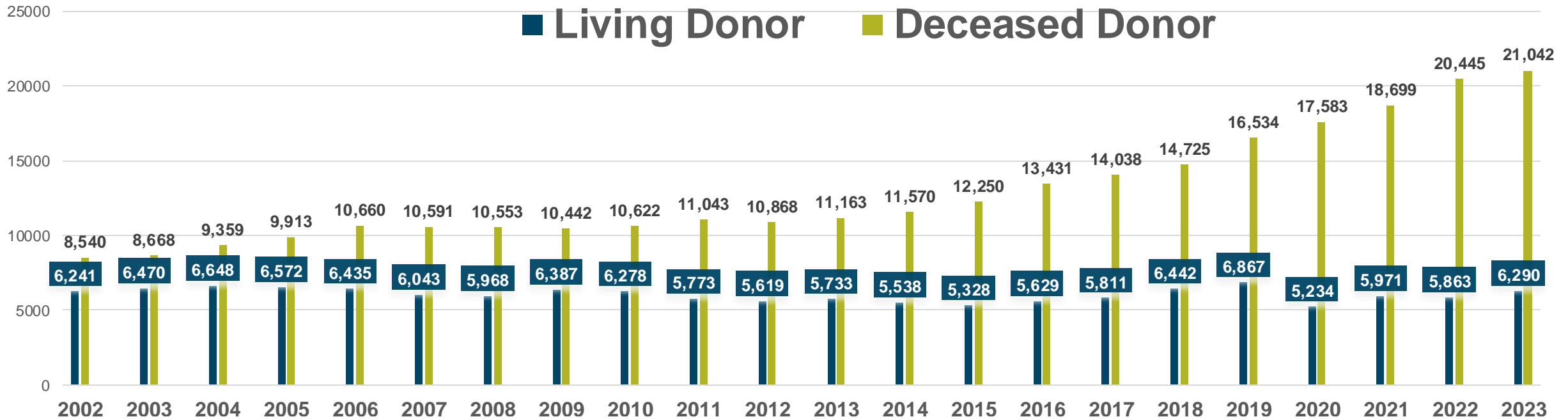
Facts: The US Kidney Transplant Waitlist

- **88,500 Americans** are on the wait list for a kidney transplant.
- **The wait list is growing faster** than the **number of kidneys available** for transplant.
 - We are reaching the limit of available organs from deceased donors; transplants from living donors are needed to reduce the wait list.
- The average wait for a kidney transplant is **3-5 years**.
- **17 people on the wait list die every day** waiting for a kidney transplant.

Facts about Living Donor Transplants

- A living donor kidney lasts twice as long (est. 16 years) as a kidney from a deceased donor (est. 8-9 years).
 - Recipients of living donation do not have to go back on the waitlist as frequently.
- A kidney transplant **saves Medicare** an estimate **\$800,000** per transplant over 10 years.
 - Doubling the living donor rate would save Medicare at least **\$6 billion over ten years.**

Living Donor Rates Have Not Moved in 20 Years -- The Current Living Donor Policy Has Failed



Billboards and Social Media Are Not the Solution

He put up a Times Square billboard in search of a kidney - and saved more lives than his own

Marc Weiner booked one of the world's most visible advertising spots, hoping his life would change. He ended up changing the lives of dozens of others, too



There are more than 253.8 million adults in the nation - most of whom presumably have a kidney to spare. Photograph: Marc Weiner

Marc Weiner has two voices. There is his speaking voice, engaging and booming, sharpened over years in front of the

The people using Instagram to find a life-saving kidney donor

Bo Harris says he was not only looking for an organ donation, he wanted to put a face to his largely invisible kidney disease



When Bo Harris needed a kidney, he reached out via social media. Illustration: Guardian Design

Bo Harris was diagnosed with chronic kidney disease in 2015. In the five years since, he has gone to countless doctor appointments, spent weeks in bed with symptoms of the illness such as severe fatigue and body aches, and even battled and beat lung cancer. But the most difficult part of the journey by far, he says, was pushing the publish button on his first Instagram post searching for a life-saving kidney donation.

"It's very out of my nature to have to ask people for anything, and for this, you have to essentially ask, 'Can you donate an organ so I can continue

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How to Use Social Media to Find a Living Donor

February 21, 2020

By Dr. Beje Thomas, Internal Medicine and Nephrology

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Melissa's Story: Finding a Living Kidney Donor Through Social Media

Apr. 14, 2022

"I do not have the words to express how grateful I am for what she has done for me," Melissa Kinnaird said of her live kidney donor. "It has really changed my life, and it has changed my life for the better."



Melissa posted on Facebook in 2021 seeking a perfect match for a live kidney



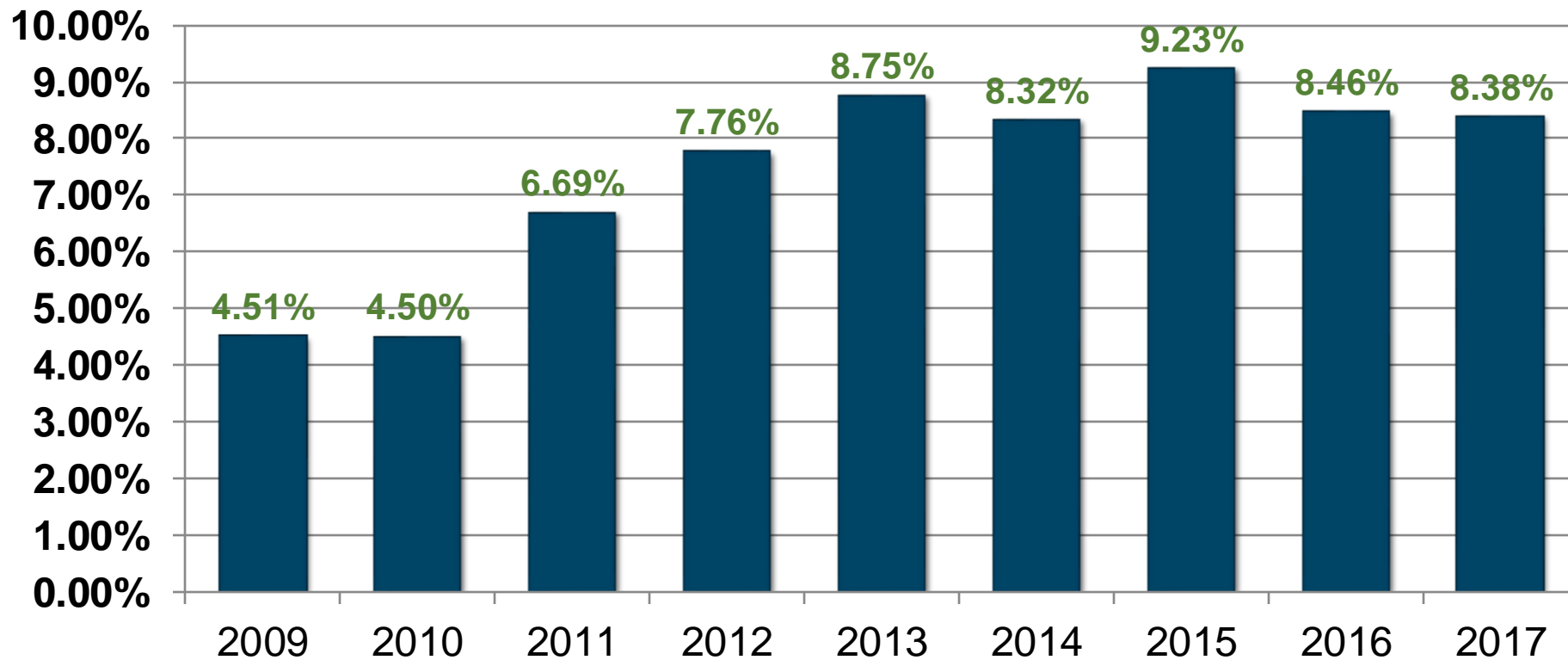
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Reimbursing Donor Costs -- the Limits of the National Living Donor Assistance Center (NLDAC)

2013 – 2017: NLDAC supports approximately 500 of the 6,000 Living Donors per year.



What Does CMS Say?

- “Kidney transplantation is considered the optimal treatment option for most ESRD patients” (*89 Fed. Reg at 43532*)
- “On average, patients experience 14 to 16 years of function from a kidney from a living kidney donor, while few people survive more than a decade on dialysis... [The] majority of deceased donor kidneys are expected to function for about 9 years.” (*89 Fed. Reg at 43532*)
- The average dialysis patient is admitted to the hospital nearly twice a year, often as a result of infection, and more than 35 percent of dialysis patients who are discharged are re-hospitalized within 30 days of being discharged. Among transplant recipients, there are lower rates of hospitalizations, emergency department visits, and readmissions compared to those still on dialysis. In general, from the standpoint of long-term survival and quality of life, a living donor kidney transplant is considered the best among all kidney transplant options for most people with CKD. (*89 Fed. Reg at 43532*)

What Does CMS Say?

- A cost advantage also arises with kidney transplantation. Per person per year Medicare FFS spending for beneficiaries with ESRD with a transplant is less than half that for either hemodialysis or peritoneal dialysis... [T]he benefits to patient survival and quality of life from living donor kidney transplantation are more pronounced...” (89 Fed. Reg at 43532)
- The increase in deceased donor kidney transplantation [over the past 20 years] was accompanied by a gradual but steady decline in the number of living donor transplants as compared to patients undergoing dialysis. The total number of living donor transplants per year has risen moderately over the past two decades, from 5,048 in 2000 to 5,241 in 2020, and 5,971 in 2021. With the overall dialysis population growing, the rate of living donor transplants per 100 patient-years on dialysis declined from 1.4 to 0.8 transplants from 2010 to 2020. A report states the proportion of patients undergoing living donor kidney donation to have decreased from 37 percent in 2010 to 29 percent in 2019. A study in 2013 of OPTN data found that the decline in living donation appeared most prominent among men, Black/African Americans, and younger and lower income adults, potentially leading to longer waiting times for transplantation, greater dialysis exposure, higher death rates on the waitlist, lower graft and patient survival for recipients, and higher overall healthcare costs for the care of patients with ESRD.
- (89 Fed. Reg. at 43533)

Problem: No National Living Kidney Donor Program

- Living kidney donation is neither nationally organized or donor-centric.
 - Individual transplant programs create and manage their own living donor programs.
 - Transplant coordinators work for the transplant hospital, and not the donor.
 - Non-profits are doing impressive work but are not moving the needle.
- The living kidney donation system lacks meaningful federal structure and support.
 - Proven model – the National Marrow Donor Program (“Be the Match”) -- which has eliminated the wait list for bone marrow transplants and saved tens of thousands of lives.
- Medicare updates are needed to support and coordinate living donor transplant.
 - Today less than seven percent of those who even complete a comprehensive living donor questionnaire will make it to the finish line.

What Could A National Program Provide?

- Transplant Navigators -- to assist ESRD patients in identifying potential living donors and help those potential donors through the process
- Appropriate Cost Reimbursement -- to ensure living donors do not have to “pay” for the privilege of donating
- National Education -- so that Americans know they can serve as living donors and understand what is involved
- A National Living Donor Database -- to maximize available living donations

The LOVE Act – a National Living Donor Program

Donor Navigators	Donor Reimbursement	Education	Coordination
<p>Builds a networks of transplant navigators to connect potential recipients with living donors and guide those donors through the donation process.</p> <p>Transplant Navigators, working as “patient illness navigators” already reimbursed by Medicare, would work with both prospective recipients and donors to complete the transplant.</p>	<p>Removes existing National Living Donor Assistance Center (NLDAC) cost reimbursement restrictions based upon the specific income limits of the donor or any income limits of the recipient.</p> <p>Expands cost reimbursement for all direct and indirect costs lost wages of up to \$2,500 per week for 8 weeks.</p>	<p>Creates a public education program to make information available about living donation for:</p> <ul style="list-style-type: none"> ➤ Educating the public about the option of living donation; ➤ Assisting in recruiting eligible living donors; and ➤ Informing potential kidney transplant recipients and professionals about the benefits of living donation. 	<p>Creates the national living kidney donation program to organize federal efforts to increase the number of transplants from related and unrelated living kidney donors.</p> <p>Modeled on the bone marrow program, the living kidney donor program would be run by a federal contractor and would implement similar policies and recruitment efforts.</p>

Questions?

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