

Congress of the United States

Washington, DC 20515

September 19, 2024

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Elizabeth Fowler, Ph. D., J.D.
Deputy Administrator and Director
Centers for Medicare and Medicaid Innovation
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Administrator Brooks-LaSure and Dr. Fowler:

We are very pleased to see the recent announcement of a proposed demonstration project to increase kidney transplants, called the Increasing Organ Transplant Access (IOTA) Model, and we applaud the Centers for Medicare and Medicaid Services Innovation Center (Innovation Center) for proposing the model. The proposal reaffirms the crisis in End Stage Renal Disease (ESRD) care and the lack of access to kidney transplant for those in need. We wholeheartedly agree with you that “low rates of ESRD patients placed on kidney transplant hospitals’ waitlists, a decline in living donors over the past 20 years, and underutilization of available donor kidneys, coupled with increasing rates of donor kidney discards”¹ lie at the root of the problem.

We were particularly alarmed at the clear documentation in your proposed rule of the “substantial disparities in both deceased and living donor transplantation rates among structurally disadvantaged populations,”² which we believe needs to be urgently addressed. It is deeply troubling to read your report that: “Black/African Americans and Hispanics/Latinos with kidney failure experience lower rates of kidney transplantation,”³ and we know more must be done to address both geographic and racial disparities in transplantation.

While deceased donation has increased approximately 250 percent in the past 20 years, living donation—a focus of your model—has not increased at all. We are optimistic about the IOTA Model, yet we remain concerned that the model design does not include the specific waivers or incentivize the needed tools to increase living donations.

There are two such ideas that have been well documented to increase the likelihood of living donation and especially preemptive donation before costly and painful dialysis is needed. First, we recommend that the model specifically provide for navigators to work with both potential transplant recipients and donors. Medicare has recently initiated coverage for Principal Illness Navigators, demonstrating a pathway for this model enhancement.⁴ These navigators could help those in need of a transplant to identify potential donors in their

¹ 89 Fed. Reg. at 43519.

² 89 Fed. Reg. at 43519.

³ 89 Fed. Reg. at 43534.

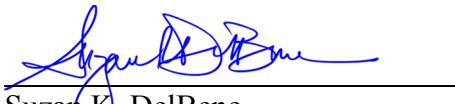
⁴ <https://www.cms.gov/files/document/mln9201074-health-equity-services-2024-physician-fee-schedule-final-rule.pdf-0>, and the program could be easily tailored for transplant navigators as well.

families and communities and help start the transplant conversation. The navigators could also work with the potential donor and assist them through the gauntlet of screenings, testing and the transplant itself. There are numerous existing small programs, from the University of Alabama Birmingham⁵ to Johns Hopkins University⁶ to numerous non-profits⁷ that are succeeding in this work, and your model could scale those remarkable programs across the entire country to significantly increase living donation.

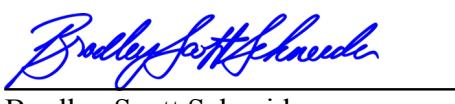
Second, the financial barriers to living donations have been well documented. The National Living Donor Assistance Center (NLDAC), funded by the Health Resources and Services Administration (HRSA), provides help for low-income individuals with follow-ups for up to two years after the transplant, as well as reimbursement for travel, lodging, meals, lost wages, dependent care, and caregiver costs. Because assistance through the NLDAC is based upon means-testing of the donor and recipient, the program's limitations prevent it from including most potential donors and covering the full breadth of transplant related expenses. While the Medicare program covers all reasonable preparatory, operation, and post-operation expenses associated with a kidney donor that are under the scope of the Medicare program,⁸ under the IOTA Model we urge you to considering reimbursing other living donor out-of-pocket costs (other than when such costs are reimbursed by HRSA or other third parties) at no cost to the transplant centers to ensure that these living donor heroes are not financially penalized or disincentivized for their generous act.

We applaud your stated goal to "increase the number of kidney transplants furnished to patients by improving or implementing greater education and support for living donors."⁹ Yet, we believe more can be done to support living donors and safeguard patients from potential unintended consequences. We welcome any questions you have about our recommendations, and you can contact our offices for additional information or further discussion.

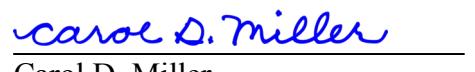
Sincerely,



Suzan K. DelBene
Member of Congress



Bradley Scott Schneider
Member of Congress



Carol D. Miller
Member of Congress



Larry Bucshon, M.D.
Member of Congress

⁵ Locke, J., et al. Enhanced Advocacy and Health Systems Training through Patient Navigation Increases Access to Living Donor Kidney Transplantation. *Transplantation*. 2020 Jan; 104(1): 122–129. doi: 10.1097/TP.0000000000002732.

⁶ Garonzik-Wang JM, Berger JC, Ros RL, Kucirka LM, Deshpande NA, Boyarsky BJ, Montgomery RA, Hall EC, James NT, Segev DL. Live donor champion: finding live kidney donors by separating the advocate from the patient. *Transplantation*. 2012 Jun 15;93(11):1147-50. doi: 10.1097/TP.0b013e31824e75a5. PMID: 22461037; PMCID: PMC3374007.

⁷ A model for veterans can be found at: <https://www.dovetransplant.org/> and a faith community model can be found at: <https://www.renewal.org/>

⁸ 42 CFR 413.402

⁹ 89 Fed. Reg. at 43549 ("We believe IOTA participants may also increase the number of kidney transplants furnished to patients by improving or implementing greater education and support for living donors").



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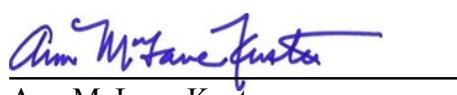
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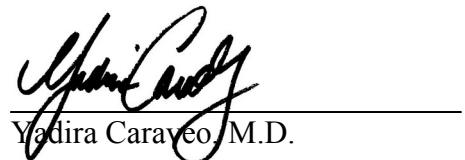
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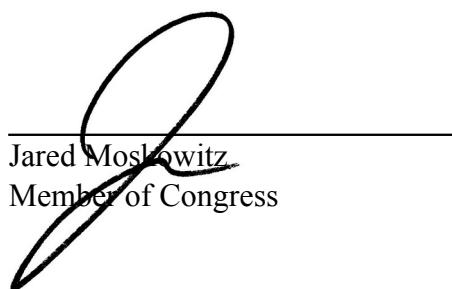
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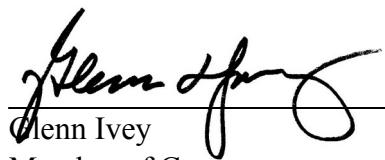
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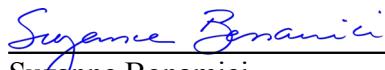
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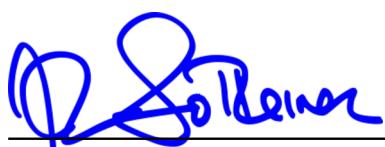
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