March 8, 2019

Dear Secretary Azar,

We write to applaud your ongoing work to increase living organ donation in the United States, and we wish to share our commitment to working with you on this vital issue. At the end of 2016, there were 726,331 people living with end stage renal disease (ESRD) and an estimated 30 million adults with some form of chronic kidney disease (CKD). Kidney transplantation is the most effective therapy for kidney failure, the ultimate outcome for many with CKD.

We were very pleased to see the Health Resources and Services Administration (HRSA’s) Healthcare Systems Bureau advance, “Lost Wages Support for Living Organ Donors Demonstration Project” (HRSA-19-069). We support further action to provide lost wages support, such as expanding the scope of the National Living Donor Assistance Center (NLDAC). The fear of unemployment or taking unpaid time off from work is a common reason cited by those who choose not to donate and is a significant disincentive to organ donation.

As you know, NLDAC provides approximately $1.9 million each year to reimburse travel expenses for eligible applicants. Last year, the program received over 1000 applications for assistance and nearly 9 out of 10 applications were approved. Importantly, 75% of these donors indicated that they would not have been able to donate without the assistance provided by NLDAC. A recent peer-reviewed study found that for each $1 spent on the program it yielded $28 in Medicare savings in dialysis costs.

It is our understanding that The Organ Donation and Recovery Improvement Act (P.L. 108-216) would allow NLDAC to be expanded to cover lost wages and other non-travel expenses of donation. If the purview of the NLDAC were to be expanded, for example, to cover lost wages, childcare, and other unreimbursed expenses incurred by a living donor, more individuals could donate and more transplants could occur saving valuable lives. We would like to work with you toward that end.

We thank you for your work to increase living donation and to address barriers that living donors face. We stand ready to work with you on strengthening the NLDAC, as well as other ways to remove disincentives so that more Americans will consider giving the gift of life, through living organ donation.

Sincerely,

Mat Cartwright
Member of Congress

Jaime Herrera Beutler
Member of Congress
Jim Himes
Member of Congress

Mark DeSaulnier
Member of Congress

Pete King
Member of Congress

Suzanne Bonamici
Member of Congress

Tim Ryan
Member of Congress

Tom McClintock
Member of Congress

William Lacy Clay
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John Lewis
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Mark Pocan
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Pete Visclosky
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Suzan DelBene
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Ted Deutch
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Tom Cole
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Tulsi Gabbard
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Vivian Clarke
Member of Congress