



STATEMENT ON COMPREHENSIVE LIVING ORGAN DONOR PROTECTIONS

March is National Kidney Month and April is National Donate Life Month. As leading, independent, national organizations representing patients, organ donors and their families, transplant surgeons, and transplant health professionals, the American Association of Kidney Patients (AAKP), the American Society of Transplant Surgeons (ASTS), the American Society of Transplantation (AST) restate our commitment to increased altruistic living organ donation through greater legal protections for a person who becomes a living organ donor. It is unacceptable that Americans with kidney failure are forced to wait on a transplant list, or die awaiting a transplant, when Congress could enact comprehensive policy solutions to remove roadblocks to living organ donation, increase available organs and save more lives.

Kidney disease and kidney failure are a threat to every American. They disproportionately impact minorities and communities of color – who already bear the burden of disparate care, health inequities and lower organ transplant rates. Increased living organ donation will save thousands of lives, and livelihoods, every year. Yet, significant roadblocks remain. Patients, potential organ donors, transplant professionals, social workers and community advocates cite practical realities and fears about job loss, insurance status including the ability to retain current or obtain future insurance, and family financial security as significant barriers to more living organ donation. **AST, ASTS and AAKP believe no person should be discriminated against for their noble decision to become a living organ donor – meaning no donor should face disparate treatment or hidden penalties for their selfless act through a threat to their job security or career, or their life, health and disability insurance or related future insurability.**

Today, we stand united to applaud Congressman Jerrold Nadler (D-NY), Congresswoman Jaime Herrera Beutler (R-WA), Senator Kirsten Gillibrand (D-NY) and Senator Tom Cotton (R-AR) for their effort to enshrine FMLA protections for all living organ donors and to increase altruistic organ donation. For National Kidney Month, these four elected leaders have re-introduced the “Living Donor Protection Act” of 2019 (H.R. 1255 & S. 377) which will protect currently insured potential living organ donors from discrimination and help patients with kidney failure. We are pleased that they have taken this important initial legislative step. We look forward to improving and strengthening the language to reflect the more comprehensive patient/donor centered solutions we have historically supported. Congress must make certain this legislation bars insurance discrimination that in any way inhibits living donation and more fully protects the patient-doctor relationship necessary to assess the risks and benefits of transplantation. The bill must prevent life, disability, and long-term care insurance companies from denying or limiting coverage and from charging higher premiums for uninsured or insured living organ donors because that person is a living donor.

Congressman Nadler, Congresswoman Herrera Beutler, Senator Gillibrand and Senator Cotton, along with AAKP, AST and ASTS know barriers to increased transplantation can be removed

through bipartisan actions that elevate and protect the interests of patients and living organ donors. In 2018, through a legal opinion, the United States Department of Labor found that the Family Medical Leave Act (FMLA) extended job protections for many Americans interested in becoming living organ donors. Last year, a bipartisan majority in Congress passed the “Comprehensive Immunosuppressive Drug Coverage” legislation which became law in December 2020. AAKP, AST and ASTS worked diligently to build grassroots and medical expert support for both of these actions which, together, protect jobs and extend lifesaving immunosuppressive drug coverage beyond a restrictive 36-month limit and provide new coverages for those who lose their insurance existing drug coverage. These actions will save hundreds of lives and prevent kidney patients from losing their organs and returning to high-cost dialysis coverage.

Congress can and should do more for living organ donation, building upon past successes to remove barriers and by removing remaining disincentives by improving, strengthening and then advancing “The Living Donor Protection Act in 2021” (H.R. 1255 & S. 377) in the 117th Congress. We hope Congress continues to listen closely to selfless Americans willing to give the gift of life and patients and families waiting anxiously for organ transplants.

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