American Kidney Fund®

March 7, 2023

The Honorable Joseph Soloman, Chairman
Rhode Island House
82 Smith Street
Providence, Rhode Island 02903

RE: HB 5489, the Unfair Discrimination against Organ Donation Act (Edwards) – SUPPORT

Dear Chairman Soloman and members of the House Committee on Corporations:

On behalf of all the people we serve in Rhode Island, including the 1,889 residents currently living with End-Stage-Renal Disease (ESRD) we are writing to **respectfully request that you support HB 5489, the Unfair Discrimination against Organ Donation Act. This important bill would prohibit life insurance companies from discriminating against people based on their status as an organ donor.**

The American Kidney Fund (AKF) is the nation's leading nonprofit organization working on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease, from prevention through transplant. With programs that address early detection, disease management, financial assistance, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF.

While most transplanted organs are from deceased donors, patients may also receive organs from living donors. Living donation offers an alternative for individuals awaiting transplantation from a deceased donor and increases the existing organ supply. Over 5,800 living-donor kidney transplants were performed last year in the United States. Kidneys are the most common organ transplanted from living donors, followed by liver and lung. Both living and deceased donation offer hope to 104,000 people (more than half the population of Providence) waiting for an organ transplant right now—including more than 88,000 who are waiting for a kidney transplant.

In addition to transforming the lives of kidney patients, a transplant is a boon to society. While people with ESRD under 65 are eligible for Medicare to manage their disease and are often forced onto Medicaid when they are no longer able to work, transplants are considered so life-altering that recipients are moved off Medicare 3 months after their successful surgery. The cost of a transplant is lower than long-term kidney dialysis, and it gives the transplant recipient a greater ability to remain in or return to the workforce.

Unfortunately, studies have shown that people who donate organs experience discrimination by insurance companies solely based on their status as an organ donor. For example, an NIH study[1]

[1] [1] Boyarsky BJ, Massie AB, Alejo JL, et al. Experiences obtaining insurance after live kidney donation. *Am J Transplant*. 2014;14(9):2168-72. *Can be found at:* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194161/

demonstrated that a high proportion of kidney donors had difficulty changing or initiating insurance, particularly life insurance.[2] The study concluded that "[t]hese practices by insurers create unnecessary burdens and stress for those choosing to donate and could negatively impact the likelihood of live kidney donation among those considering donation."[3] Further, extensive research has demonstrated that people who donate a kidney are likely to live just as long as similarly healthy people who have both kidneys.[4]

We believe that providing incentives and removing financial burdens for living donors can lead to an increase in organ donations. For these reasons, **we are hopeful for your support of legislation that could help improve the lives of those fighting kidney disease.**

Thank you again for your leadership and for your consideration of this critical issue.

Sincerely,

Jon Hoffman
Senior Director of State Policy and Advocacy

[2] *Id.*
[3] *Id.*
[4] Segev DL, Muzaale AD, Caffo BS, et al. Perioperative Mortality and Long-term Survival Following Live Kidney Donation. *JAMA.* 2010;303(10):959–966. doi:10.1001/jama.2010.237. *Can be found at:* https://jamanetwork.com/journals/jama/fullarticle/185508