

February 10, 2021

The Honorable Matthew L. Lesser, Co-Chair
The Honorable Kerry Szeps Wood, Co-Chair
The Honorable Saud Anwar, Vice-Chair
The Honorable Robin E. Comey, Vice-Chair
Members
Connecticut General Assembly Insurance and Real Estate Committee

RE: Support for HB 6387 to protect living organ donors

Dear Insurance and Real Estate Committee Members:

As a kidney dialysis patient residing in Montville, a Patient Ambassador of Dialysis Patient Citizens and on behalf of the more than 6,300 fellow Connecticut residents with End State Renal Disease (ESRD), I write to ask your support of HB 6387 which would prohibit certain insurance companies from discriminating against living organ donors.

Dialysis Patient Citizens (DPC) is a national, non-profit advocacy organization working to improve the quality of life for all dialysis patients through education and advocacy. DPC is a patient-led organization with membership open only to ESRD and dialysis patients and their families. DPC's mission and policy positions are guided solely by its membership and Board of Directors that is comprised entirely of ESRD patients.

Passage of HB 6387 would help remove one of the existing barriers to organ transplants so that more ESRD patients could receive a kidney transplant from a living donor. Patients such as myself with ESRD, or kidney failure, must receive dialysis treatment three or more times per week or receive a kidney transplant just to survive. Of the nearly half a million ESRD patients nationwide who are receiving dialysis, approximately 100,000 of them are currently awaiting a kidney transplant.ⁱ More than 1,000 of these patients reside in our state.ⁱⁱ Sadly, only a fraction of patients on the waiting list receive a kidney transplant each year.ⁱⁱⁱ

Living kidney donors are desperately needed because the number of ESRD patients waiting for a transplant is far greater than the number of kidneys that become available through deceased donor matches alone. In addition to increasing the supply of kidneys available for transplant, living kidney donations can significantly decrease the wait-time for patients to receive a transplant, thus reducing the number of patient deaths among those waiting for a transplant and lowering health care costs of prolonged dialysis treatments. Moreover, patients who receive a kidney from a living donor have greater kidney longevity and fewer complications than those who receive a kidney from a deceased donor. This, too, helps lower health care costs and allows patients to live a better quality of life.

In Connecticut and numerous other states that don't yet have statutory protections in place, living donors commonly experience insurance discrimination based solely on their status as a living donor,

which makes it difficult for them to obtain and/or change health and life insurance, particularly the latter.^{iv} This discriminatory practice reduces the likelihood that a person will donate an organ since doing so would create a financial burden to them. Fortunately, HB 6387 seeks to prevent insurance companies from declining or limiting coverage or determining premium health plan rates based solely on a person's status as a living organ donor.

We look forward to working with legislators on this important issue and to find policy solutions to address some of the other barriers that serve as an impediment to transplant, such as the inability to demonstrate sufficient insurance coverage or financial resources needed to cover the cost of post-transplant medical care and immunosuppressive therapies, which could be largely resolved simply by ensuring Medigap access for all ESRD patients.

If you have any questions or would like information about cost-effective ways we can help improve health outcomes for ESRD patients in Connecticut, please feel free to contact Elizabeth Lively, Eastern Region Advocacy Director at Dialysis Patient Citizens at 312.890-1428 or elively@dialysispatients.org.

I urge you to support HB 6387 since it would remove one of the many barriers that prevent ESRD patients from receiving a life-saving kidney transplant.

Sincerely,

Stephanie Shabanowitz

Patient Ambassador, Dialysis Patient Citizens
Montville, CT

xc: Hrant Jamgochian, CEO
Dialysis Patient Citizens

ⁱ <https://kidneycarepartners.com/kidney-disease/>

ⁱⁱ <https://optn.transplant.hrsa.gov/data/view-data-reports/state-data/#>

ⁱⁱⁱ <https://pharm.ucsf.edu/kidney/need/statistics#:~:text=In%202016%2C%2020%2C161%20kidney%20transplants,has%20not%20grown%20to%20match.>

^{iv} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194161/>