

Good morning, I'm Sue Hendon and I would like to thank Chairman Vickrey for the opportunity to speak in support of the Living Donor Protection Act, House Bill 2041. I am testifying on behalf of the National Kidney Foundation and living organ donors like myself. The National Kidney Foundation is the largest, most comprehensive and longstanding, patient centric organization dedicated to the awareness, prevention and treatment of kidney disease in the US.

I became a kidney donor in 2009. I was at Costco when I ran into my friend Mary Long, who told me how her husband Ed needed to start dialysis despite having managed his kidney disease for years through strict adherence to his kidney diet. I volunteered to be tested on the spot.

Chronic kidney disease (CKD) affects more than 30 million Americans, approximately 90% of those with kidney disease don't even know they have it. It causes more deaths than breast cancer or prostate cancer. In Kansas, more than 43,500 kidney patients on Medicare have CKD. Transplants not only save the lives of dialysis patients and greatly improve their quality of life, but they also save Medicare more than \$55,000 per year, per patient when compared to kidney dialysis patients.

A kidney transplant is a patient's only lifesaving treatment other than dialysis. Nearly 300 people are waiting for a kidney – 3 of every 4 people waiting for an organ transplant - in Kansas. Last year, only 118 Kansans received a kidney transplant. Once you are put on the transplant list, the average waiting time is 3 to 7 years. Average life expectancy on dialysis is 5 to 10 years. The math is sobering. The clock is ticking for each and every one of those 300 patients on the waitlist. Everything we do to help encourage living donation saves lives.

Patients seeking a transplant talk to their family, friends, colleagues, and even total strangers. Potential donors go through extensive testing. Ed and Mary waited for 6 weeks while they tested him to make sure he was healthy enough to benefit from a transplant. They tested me to make sure that being a kidney donor

would not impact my health. Transplant doctors will not remove an organ if it's going to harm the donor.

Both my recipient and I lead a full life, without much limitation. I continued to work, until my retirement. I volunteer in my community, paint, play racquetball, run triathlons, and spend time with my family. I am here today to serve my community by protecting altruistic Americans, like myself, who made the gift of life to save another person's life.

A 2014 study by Johns Hopkins University showed that a quarter of living donors in the study faced discrimination when they tried to obtain or change their life insurance just because they were organ donors. Additionally, the National Kidney Foundation regularly hears from living donors who experienced premium changes or other restrictions on their insurance policies.

One story is from a National Kidney Foundation Board member in Missouri who donated to his wife. After his donation, he applied for an additional \$250,000 life insurance policy and went through the application process in which he disclosed the donation. The insurance company declined to provide the requested insurance coverage. Only after he complained and threatened legal action, the insurer agreed to provide the coverage. The quoted annual premium was \$25,000. The insurance company likely knew that by quoting the insurance at such a high premium, he would decline the policy. By comparison, the annual premium for a policy that he had in place before the donation for \$500,000 of insurance was \$760. Quite the difference.

One of NKF's Past-Chairman also experienced complications when he tried to obtain life insurance after donating to his brother. When he applied, the company denied him based on his status as an organ donor. It was only after intervention by his nephrologist that the company agreed to provide him with the requested life insurance plan.

Kansas public policy encourages organ donation. State civil servants are provided 30 days paid leave to donate an organ and donors are provided an income tax

deduction to help recoup unreimbursed expenses related to donation. However, the possibility of increased insurance premiums discourages organ donation. This must change. HB 2041 would prohibit discrimination against organ donors based on their status as a donor. It simply prohibits discrimination based solely on a person's status as an organ donor.

I request your support of HB 2041 to let potential donors know beyond any doubt that donating to save the life of a Kansan will not cause economic hardship. Let donors know that they don't have to worry about their premium increasing or their policy being denied or cancelled. Living organ donors should not experience economic hardship or discrimination for their act to help a friend for family member in need. Please support House Bill 2041.