

Testimony of the National Kidney Foundation
H.B. 399, to Expand Opportunities for Living Organ Donation
Presented to the Committee on Ways and Means
May 14, 2024

Mr. Chairman and members of the committee, thank you for the opportunity to testify today on House Bill 399 to address barriers to living organ donation and enable more people to receive the Gift of Life. I am Mari Artinian and am honored to appear before you today on behalf of the National Kidney Foundation.

An estimated 37 million U.S. adults have chronic kidney disease, 540,000 of whom are on dialysis, where they commonly face multiple challenges and comorbidities. Many dialysis patients are too sick to work, exacerbating financial and personal hardships and a sense of independence. Quality of life is poor and commonly includes cognitive challenges (“brain fog”), depression, infection, dietary restrictions, anemia, and post-dialysis fatigue. Further, dialysis has a 5-year survival rate of under 50%, while a kidney transplant recipient has a 5-year survival rate of about 80%. Many kidney recipients live three or four times longer than that.

Kidney disease is the nation’s 10th leading cause of death, including 12 people a day who die on a kidney transplant wait list. In our state, more than 19,000 people require dialysis and almost 2,000 are on a transplant waiting list. Last year, 1,329 Ohio residents received a

kidney transplant. To date, 293 kidney transplants have occurred this year, 59 of which were possible by a living donor. Living donation has the best outcomes compared to a deceased donor transplant or to dialysis, but only 1 in 4 transplants nationwide are made possible by the generosity of a living donor. Living donation represents the best opportunity to significantly increase the number of kidney transplants, but only if barriers are removed.

My husband Chris, is one such case. Chris was diagnosed with Kidney Disease about 15 years ago. A combination of obesity and excessive Motrin usage was the cause. At the time, we really never even thought about how serious kidney disease is. I am a college educated woman, and quite honestly, I thought that dialysis was a solution and never gave it much thought. Boy, I was wrong.

Up until November 2022, life was very normal for our family. My husband is a President & CEO and travels quite extensively. He lifts weights, plays tennis, & is learning how to box. His visit to the cardiologist that fall showed unusual red blood cell activity, and he was referred to an oncologist. The thought was he had some type of blood cancer. After many numerous tests and a bone marrow biopsy, the medical team had concluded that it was in fact, his kidneys wrecking havoc on his system. We were warned that now would be the time to start with a transplant center. Chris was adamant regarding dialysis - he did not want to do it. So we registered with OSU transplant center, myself, my five children, my brother in law, and an anonymous donor. We couldn't be seen until Chris was accepted by the center. We had no idea this would take months, not days or weeks. I pushed and pushed. He had an appointment for the middle of June. Our goal was to have Chris transplanted before he ever needed dialysis. The doctors weren't sure, but optimistically guarded.

On April 25th, 2023, our lives completely changed. Chris was in renal failure. A myriad of information was being thrown at us. I didn't understand how to navigate this new world. In addition, this happened so very quickly, Chris couldn't process what was happening. We were told that he had to have a catheter put into his heart immediately and at least have one dialysis treatment before the weekend. In Dr. Mussio's own words " I don't know if he will make it the weekend. His numbers are terrible. I don't know if he will wake up". Terrified

doesn't begin to cover my emotions. In addition, we never thought we would be here, so we were not educated, not knowledgeable.

He was rushed to have a port in, and in speaking with the nurses, we told them that Chris had 7 living donors willing to go through the process. The nurse was in tears. I didn't understand why. It didn't make sense. If you could do something to help a family member, without harm to yourself, why wouldn't you do it? She said Chris was the anomaly. I still didn't comprehend what she was saying

After that, it was getting Chris on a dialysis schedule with home dialysis as the goal. Chris needed the freedom to dialyze at 2 in the morning, if needed to catch a flight at 9 am. At the dialysis center, once again, we learned that living donors are RARE.

While this was going on, I was trying to advocate for Chris and push to have his donors tested asap. This wasn't easy. I didn't know it would take so much time. The amount of time that each donor testing takes was never really explained. Again, we are talking about months not days or weeks.

The first one up was my son, Peter, who lives in Chicago. OSU felt he would be the perfect candidate at the time. Peter would fly or drive back and forth for all testing. The time commitment, days off, and travel didn't go unnoticed. This process took about a month and a half.

Peter works for United Airlines. He explained his situation to the company, and they were willing to work with him. He would get the time off, but it would be unpaid. But Peter decided that he would work around that "little issue" and do whatever he could to help his Dad. In the end, after a few flights, a few drives from Chicago to Columbus, it was determined that Peter would not be a suitable candidate. He was rejected by the committee. We thought we were at the finish line and we had to start over again with a new donor.

So, next up to bat was me. This would be a perfect solution, as I wouldn't have to take any time off, not worry about losing wages, and I lived here in Delaware. The only drawback was that my children would see both parents go through surgery. They were very leery. I told them this was the best solution. Chris and I were a match, and the phrase "til death do us part" was quite literally, becoming a reality. I was near the finish line, we were looking at a November surgery date, and life threw us a curveball. My very healthy Dad was hospitalized with his own kidney issue. My blood pressure rose, & the medical team wasn't comfortable with my numbers. All that time wasted again. But when I was going through testing, I was

adamant that my son, Joey be tested along with me. I saw how much time and money it took for Peter, and I wanted to hedge our bet. My goal was to get Chris transplanted as soon as possible and with the right match. God was truly looking over us, and when my “life event” occurred, Joey was able to fly out and resume testing- he was at the same point I was in testing terms. He was the perfect match for Chris.

Joey is the Director of Lacrosse Operations at Marquette University. He lives in Milwaukee. Once again, the expense Joey relinquished to help his Dad is amazing. He flew out several times at a moments notice at a considerable cost. Once again fate would step in and Joey scheduled the surgery for November 28th, 2023. The reason I say “fate” is because that is Thanksgiving break for the University. The University worked with him & he would be able to take the time off until after Winter Break. Joey was able to work from our home while recovering. We were very lucky. He would still be paid by his employer- a key issue for a 23 year old kid with student loans.

Once again, on the transplant floor at OSU, we were told that there weren’t many living donors. Certainly, the nurses claimed, Joey was probably the youngest to donate. Joey is my hero. Actually, all my kids are. They all stepped up willing to do what they could.

In the end, we were extremely Blessed. We were Blessed because there were so many of us who were willing to do whatever it took to help Chris during this adventure. There aren’t many of us out there. For the majority, it is a real financial expense to commit to donating an organ. Money and time off is truly an obstacle, and if we can remove barriers, this would be a major one.

Financially, this makes sense. Do you know it cost Cigna \$24,000 a week to provide dialysis to Chris? This bill makes sense. Yes, the output is upfront, but in the end, you are taking someone off of dialysis and making them a productive member of society. I know our story is unusual. Chris never slowed down, still ran a company, sat on boards, had 7 procedures in that time frame, and missed only 2 days of work (before the transplant). There aren’t many who could say that. He’s pretty amazing Another hero in my book

Now, he is back at work, fully recovered, not tethered to a machine. Life is back to “normal” again. Please, I implore upon you, remove the barriers. This bill could change a persons

life. Someone who might be constrained by financial issues could have the ability to make the decision to donate without worrying. The donor should be made whole, not more, not less. This bill would make them whole.

The creation of a tax credit for employers who provide paid leave for employees who become living donors in Section 5747.74 is a positive step towards removing a significant barrier to organ donation. Living donors should not suffer financial loss or hardship for their selfless act, and allowing donors to take medical leave without fear of lost income removes a significant barrier to donation. The National Kidney Foundation provides up to 30 business days of paid leave for employees to serve as a living donor, and we applaud encourage employers to include such supportive policies as an employee benefit.

Additionally, I appreciate the bill sponsors' decision to maintain the existing law that ties the individual tax deduction to reimbursement of qualified expenses related to organ donation. We look forward to reviewing and supporting this updated version of this legislation.

The National Kidney Foundation (NKF) has a long history of advocacy in support of personal income tax deductions and credits to offset unreimbursed expenses that result from a living organ donation. Maintaining the current provisions in Section 22 upholds the essential principles of ethics, informed consent, and preventing organ trafficking.

Tax incentives can increase donation when properly structured, as in the case of the employer leave credit, which supports living donation in an ethical manner. In closing, we

appreciate your consideration of these perspectives and your leadership in helping more people receive a life-saving organ transplant.

Thank you.