Protecting Donors and Safeguarding Altruism in the United States
The Living Donor Protection Act

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The present state of transplantation in the United States can be most easily summarized as “good news/bad news.” On the positive side, improvements in short-term outcomes have translated into measurable improvement in long-term survival (1), new allocation schema have increased opportunities for disadvantaged populations (2), and the absolute number of transplants performed annually continues to increase (3), in part due to strategies that facilitate living donation. The bad news, of course, is that these improvements are dwarfed by the growth of those waiting in need of a transplant (4). Although efforts to increase deceased organ donation are important, it would take fundamental changes in deceased donor management or clinical practice to more substantially affect the “need gap” via deceased donation. Efforts to facilitate living donation, specifically by reducing any barriers to living donation, are much more likely to affect transplant rates, thereby increasing the opportunity for patients with ESKD to receive the most optimal and cost-effective therapy. To this end, the American Society of Transplantation helped draft and drive introduction of the Living Donor Protection Act (LDPA). The LDPA, introduced in March of 2017, states as a primary goal “to promote and protect from discrimination living organ donors.” This bill addresses three key issues affecting living organ donation. If passed into law, it would (1) render unlawful declining, limiting coverage, or charging higher premiums from a living organ donor under any life, disability, and long-term care insurance policy by insurance companies; (2) amend the Family and Medical Leave Act (FMLA) to clarify that the organ donation surgery qualifies as a serious health condition that entitles coverage under that act; and (3) mandate the development of updated educational materials on live organ donation in an effort to educate the public on the benefits of live organ donation and encourage more individuals to consider donating an organ.

These provisions are vitally important for the potential living donor to make informed decisions regarding the pursuit of donation. They would allow the prospective donor to consider the gift of organ donation with assurances of proper education of the risks and benefits of donation as well as freedom from future discriminatory practices by both employers and insurance companies. Regarding the former point, progress has been made in formalizing the educational process after a prospective donor has entered the evaluation process (https://optn.transplant.hrsa.gov/media/1200/optn_policies.pdf#nameddest=Policy_14), and scientific guidelines have also been updated to provide a consistent framework of the risks and benefits of living donation to ensure that transplant centers are able to obtain consent from the prospective donor that is truly informed (5). The missing element, addressed with the LDPA, is a more global educational effort to the general public that places living donation in appropriate context. Despite general awareness of living organ donation (approximately 75% of the general population is aware of living organ donation as reported in one meta-analysis [6]), studies using focus groups and focused interviews of the general public consistently identify public misperceptions and a lack of knowledge regarding the risks of organ donation (7). Ideally, well described public policy positions regarding living donation that would emanate from the LDPA would narrow this knowledge gap and help increase living donation awareness.

Although misperceptions regarding the surgical and health risks of donation exist, very real issues of financial consequences also contribute to negative or ambivalent public perceptions of living donation. Multiple financial barriers exist for the living donor, including costs of travel and lodging for medical evaluation and surgery, lost wages, and the expenses associated with dependent care during the recuperation period. The LDPA would address one element of this financial burden (protection from the prejudicial assignment of a “preexisting condition” for insurance premiums) and offers security from loss of employment and benefits. Moreover, it preserves the core tenet of living organ donation, altruism, a shining example of the “belief in or practice of disinterested and selfless concern for the well-being of others.”

This latter point is important. Often, misrepresented ethical concerns stand in the way of progress when discussing efforts to facilitate living organ donation. One ethical consideration that is often raised is whether a given intervention acts as an inducement
or could be considered as coercive, thus diminishing the altruistic act of donation and potentially negatively affecting public attitudes toward living donation. Examples in the past have included guaranteed health insurance, an income tax credit, or a fixed payment as an organ donor (8). The discussion of payment for lost wages has been tested in this context as well, but recent public opinion combined with supporting language within the National Organ Transplant Act of 1984 (NOTA; P.L. 98–507) have led to pilot programs exploring this forward step (9). An overarching philosophy has emerged that organ donation should be financially neutral for donors, not imposing financial burdens while specifically not offering “valuable consideration” (10), which is described in the NOTA as “it shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce.”

Importantly, “valuable consideration” does not include the “reasonable payments associated with the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ.” The LDPA does not tread into these ethical murky waters of inducements versus reasonable payments by maintaining the well accepted concept of “net neutrality” for the living donor (11). In this manner, the passage of the LDPA reflects society’s perspective toward living organ donation and facilitates the donor’s altruism.

At face value, the LDPA would seem to be a very logical next step in easing the burden of living organ donation with little debate. After all, it was successfully introduced in the House of Representatives with bipartisan support (with Jerrold Nadler [Democrat; New York] as the lead Democrat sponsor and Jaime Herrera Beutler [Republican; Washington] as the lead Republican sponsor), despite ongoing political turmoil regarding health care, and it has subsequently garnered further bipartisan support from 54 cosponsors as of December of 2017. Unfortunately, on its introduction, it was referred to no fewer than five committees for review (the Committee on Oversight and Government Reform, the Committee on House Administration, the Committee on Education and the Workforce, the Committee on Oversight and Government Reform, the Committee on House Administration, the Committee on Energy and Commerce, and the Committee on Energy and Commerce, which subsequently referred it to the Subcommittee on Health). Such a diffuse process for review makes the bill vulnerable to inertia and lack of attention. Alarmingly, according to a review by a text analytics firm (Skopos Labs), the bill has a 1% chance of being enacted in its present form. Not only does it face an uphill battle in negotiating the political process, additional pressure from lobbying interests for small business and insurance companies could conceivably influence the process. Arguments that could be made include (1) that organ donation does not constitute a “serious illness” that the FMLA should be expected to cover (the FMLA stipulates up to 12 weeks of unpaid leave, with benefits, to recover from a worker’s own serious illness and the right to return to his or her job) and (2) that organ donation does, in fact, constitute a health condition that should be considered when underwriting insurance policies. Although arguments could be made on both sides, perhaps a simple analogy to counter these points would be to compare living donation with caring for a new child after adoption, which is covered by the FMLA and not discriminated against by insurance companies. Similar to living organ donation, this act, carried out volitionally with its roots as an act of giving that requires substantial screening before approval, which may require additional medical services related to the act of adoption (which are rare and not predictable) and is fully supported under the FMLA, is an act of altruism that deserves protection.

What is next for the LDPA? Currently, there are 54 cosponsors of the LDPA in the House as of December 1, 2017, up from 36 in August 2017. In July 2017, the American Society of Transplantation, the American Society of Nephrology, the American Society of Transplant Surgeons, the National Kidney Foundation, Waitlist Zero, and the Renal Physicians Association signed a coalition letter of support to build support on the Hill to drive the bill forward. In the absence of breaking down the bill into smaller component parts, the most effective strategy at this point is to continue to gain attention and support from as many members of Congress as possible and maintain the bill’s momentum as a bipartisan effort front and center in health care discussions (ideally, a companion Senate bill would be introduced to accelerate the process). We are consistently reminded that all politics are local; thus, grassroots efforts to educate representatives and prioritize the bill will be essential in this regard to secure the protections that our living kidney donors deserve.

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