

# THE LIVING KIDNEY DONOR SUPPORT ACT

## SECTION BY SECTION

### THE ISSUE:

As of 2022, there are approximately 93,000 Americans waiting for a kidney transplant, with tens of thousands more in need of a transplant not on the waiting list. The average wait is 3-5 years, and 12-17 persons die each day waiting for a kidney transplant. The waiting list is growing faster than organs from deceased donors are becoming available. While more needs to be done to improve kidney recovery from deceased donors, the shortfall in life-saving kidneys can be closed if living donation increases. Living donation is safe, ethical, and has been successful for decades. Yet, while deceased donation has more than doubled in ten years, the number of live kidney donations has not increased in twenty years.

Living kidney donation today is a failed and inconsistent enterprise spread across non-profits, transplant centers, and other entities. Comprehensive national legislation is needed to integrate and coordinate public and professional education, to create a patient navigator program supporting potential living donors, to improve reimbursement of costs for living donation, and to conduct necessary studies and other activities to create a program which is effective for potential donors, transplant professionals, and the hospital centers which care for living donors.

### THE LEGISLATION – SECTION BY SECTION:

The Living Kidney Donor Support Act will create a new Section 275 of the Public Health Service Act, modifying the existing law to fit living kidney donation, as follows:

#### **Section (a) – *The National Living Donor Program:***

Creates the national living kidney donation program (the “Program”), to increase the number of transplants for recipients suitably matched to related and unrelated live kidney donors, to provide patient navigators and other assistance to living kidney donors, and for other purposes. The Program is directed to retain one (or more) contractors to operate a national public and professional educational program to both attract and secure living donors, to build out local and national networks of living donor navigators to guide donors through the entire donation process, to improve cost reimbursement for all aspects of living organ donation, and for the other purposes of the living donor program.

#### **Section (b) – *Education:***

The provision instructs the Secretary, through a contractor, to undertake needed national public and professional educational activities to make information available about living donation, to train individuals to educate the public about the option of living donation, to assist in recruiting eligible living donors, and to educate potential kidney transplant recipients and the professionals who serve them about living donation as a treatment option.

#### **Section (c) – *Program Details:***

This section sets the operational details of the Program, including recruiting and screening donors, creating a national system to match living donors to recipients in need, create the living donor navigator system (addressed in more detail in section (d)), and creating a single point of national coordination. The section:

- creates a simplified enrollment and eligibility system for potential living donors, including at home testing and central laboratories that can perform needed medical tests;
- acknowledges the important role that living donor non-profits have served, and instructs the Secretary to continue to work with the non-profit sector while including non-profits in the national program;
- requires the Secretary to respect the wishes of living donors in directing their donated organ to a family member or other specific community (such as veterans);
- assures that transplant center and transplant hospital costs are appropriately reimbursed for costs associated with the program; and
- requires the Secretary to consider the roles and needs of medical professionals, including transplant surgeons, nephrologists, and other relevant physician specialists.

**Section (d) – Donor Navigator Office and Navigator Requirements:**

This section sets the details of the living donor navigator “Office” within the program. The Office will train qualified individuals to serve as donor navigators and assign a navigator to each qualified and eligible living donor progressing through the living donor program. Navigators will assist on streamlining medical testing (including prioritizing testing at home to the extent medically appropriate), and assist the donor through and following the donation surgery. The Office will interact with navigators who are appropriately trained and who are employed by transplant centers, non-profit organizations, and other local or regional entities committed to guiding potential donors throughout the process of organ donation.

**Section (e) – Living Donor Cost Reimbursement:**

The Program is to coordinate with the existing National Living Donor Assistance Center (NLDAC) to expand cost reimbursement for all direct and indirect costs, including lost wages of up to \$2,500 per week, life and health insurance for any care following donation necessitated by the nephrectomy, and amendment of the NLDAC statute to eliminate restricting cost reimbursement based upon the specific income limits of the donor or any income limits of the recipient.

**Section (f) – Data:**

This section requires the collection of data about living donation, and coordination with the existing Scientific Registry of Transplant Recipients.

**Section (g) – Regulations:**

This section requires the Secretary to issue regulations to establish patient navigator standards, confidentiality standards specific to living donation, and standards to coordinate the Program with transplant hospitals, OPOs, non-profit organizations and other entities involved in kidney donation.

**Section (h) – Advisory Committee:**

This provision requires the Secretary to consult with relevant stakeholders, including the Advisory Committee, the National Marrow Donation Program, the Departments of Defense and Veterans Affairs, the existing not-for-profits engaged in living kidney donation, and others, to improve Program operations.

**Section (i) – Contracts to Run the Program:**

This provision requires the Secretary to solicit contract bids for the operation of the Program. Because they are focused on serving recipients, the existing operator of the OPTN and OPOs are precluded from operating the Program, and the National Living Donor Assistance Center is authorized to continue to operate as a separate contractor within the Program.

**Section (j) – Recordkeeping:**

This provision requires the Secretary to establish recordkeeping requirements related to the Program.

**Section (k) – Advisory Council:**

This provision establishes an Living Donor Advisory Council to assist the Secretary.

**Section (l) – Studies:**

This section requires the Secretary to study potential expansion of the living donor program overseas, and to analyze long term health outcomes of living donation.

**Section (m) – Coordination on Visas:**

This section requires the Secretary to coordinate with the Secretary of Homeland Security to facilitate visas for foreign living donors wishing to donate to an American.

**Section (n) – Definitions:**

This section defines key terms in the statute.

**Section (o) – Appropriations:**

The provision appropriates funds (in an amount to be determined) through calendar year 2031 to operate the Program.

**Section (p) – Conforming Amendments:**

This section is reserved for necessary conforming amendments.

**Section (q) – Expansion to Liver Donation:**

This section authorizes the Secretary to expand the kidney living donor program to liver living donors at an appropriate time.

**FOR MORE INFORMATION,**

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