

# What You Need to Know About the Living Donation Proposed Rule

#### What's being proposed?

The Health Resources and Services Administration (HRSA), an agency of the Department of Health and Human Services (HHS), is proposing to help remove barriers to living donation by expanding the types of expenses that living donors can be reimbursed for under HRSA's Reimbursement of Travel and Subsistence Expenses Incurred toward Living Organ Donation Program, commonly known as the National Living Donor Assistance Center (NLDAC).

#### What are the specifics?

The proposal would expand the types of expenses associated with living donation that can be reimbursed by <a href="NLDAC">NLDAC</a> to include lost wages and child-care and elder-care expenses incurred by a primary caregiver. Currently, qualifying expenses for reimbursement are limited to travel, lodging, meals, and incidental expenses incurred by the donor and/or accompanying person(s) associated with donor evaluation, hospitalization and/or medical or surgical follow up within two years following the living donation procedure. In addition, those seeking support from NLDAC must meet income eligibility thresholds.

### Why does this matter to patients?

Receiving an organ from a living donor is a critically important option for patients whose kidneys have failed who otherwise would be faced with waiting for a deceased donor organ or dialysis. Despite the value of living donation, living donors incur numerous expenses associated with the procedure, a significant barrier that may preclude otherwise interested donors from donating. HRSA estimates that the proposed changes would result in a four to six-fold increase in the number of applicants to NLDAC, resulting in a commensurate increase in the number of potential living donors.

#### Why is this happening?

As part of the Advancing American Kidney Health (AAKH) initiative, the Administration has committed to reducing the number of patients waitlisted for organs by increasing the number of organs available for transplant. Transplants with living donor organs constituted approximately 19 percent of transplants in 2018. The Administration hopes to increase the number of patients receiving transplants by eliminating some of the financial barriers to living donation. This proposed rule fulfils a requirement of the AAKH initiative, which directs HHS to propose a regulation to support living donors.

### What has NKF done on this issue in the past and what are next steps?

Advocating for living donors and reducing barriers to living donation are longstanding NKF priorities. NKF supports this proposal to expand reimbursable expenses and will continue to advocate for the elimination of other barriers, financial and otherwise, to living donation. NKF will also advocate to increase the funds available under the NLDAC program to ensure that every living donor who needs financial reimbursement for donation-relation expenses will receive it. NKF also leads the charge to pass the <u>Living Donor Protection Act</u>, which would prohibit insurance companies from denying, limiting, or charging higher premiums to living



organ donors for life, disability, and long-term care insurance and clarifies that living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from donation.

NKF will work with our Public Policy Committee to submit comments on the proposed rule. We welcome your input! Please contact Miriam Godwin (<u>Miriam.godwin@kidney.org</u>) to share your perspective on these proposed changes.

## Where Can I Learn More?

See <u>NKF's statement</u> on the proposed rules. View <u>HRSA's summary</u> of the proposed rule or view the <u>full</u> <u>document</u>. In addition, feel free to reach out to Miriam Godwin (<u>Miriam.godwin@kidney.org</u>) with questions or concerns.