

HRSA STAKEHOLDER MEETING

Last year, the number of living kidney donors dropped to the lowest amount since 2000, when barely half as many patients were on the transplant waiting list. Clearly, a breakthrough in living donation policy is necessary. The Health Resources and Services Administration (HRSA) is the federal agency with primary responsibility for organ donation. Improving living donation policy requires their cooperation and support.

Unfortunately, HRSA has not made the same type of unreserved commitment to promoting living donation as for deceased donation, in part because of concerns about topics such as incentives and donor safety. Our campaign aims to provide stakeholder coverage and support to HRSA to allow them to effectively pursue living donation goals.

Living Donation Policy Goals

Several promising policy initiatives exist to improve support for living donor transplant:

- Dissemination of transplant center best practices throughout the field;
- Removal of financial disincentives to donation such as lost wage, travel, and childcare expenses;
- Requiring independent and comprehensive transplant education for all medically eligible patients and their families;
- Guaranteed lifetime health coverage for living kidney donors; and
- Improved follow-up care and study of living donors.

HRSA cooperation and support is a necessary precursor to achieve these long-term goals. The campaign also seeks to build infrastructure for transplant, patient and donor interests to advocate in tandem for living donation policy in the future.

Stakeholder Meeting

The stakeholder meeting that our Coalition, the AST, ASTS, Donate Life America, and the NKF have asked HRSA to hold is intended to demonstrate the need for improved living donation policy and demonstrate consensus on actionable steps HRSA can take in the short term. We envision those actionable recommendations to be HRSA's:

- Sponsorship of a Living Donation Breakthrough Collaborative;
- Support for expanding NLDAC to cover lost wages and childcare expenses;
- Inclusion of living donation goals in HRSA's Annual Performance Report; and
- Consideration of projects that promote living donation for 274f-1b grant funding.

Campaign Specifics

In addition to holding a stakeholder meeting with HRSA, support and urgency around living donation will also be demonstrated via:

- Outreach to federal legislators, including soliciting their signatures for a letter in support of living donation policy; and
- Awareness-raising efforts in the media around the campaign and living donation.