



# WAITLIST ZERO



WaitList Zero  
2545 Hillegass Ave.  
Berkeley, CA 94704

October 14th, 2014

Robert Walsh  
Division of Transplantation  
Health Resources and Services Administration  
5600 Fishers Lane  
Rockville, MD 20857

Re: Living Organ Donation Inquiry Letter

We write as a group of organizations representing organ donors and recipients with a mutual interest in promoting living kidney donation. We wish to formally inquire about HRSA's involvement with living kidney donation.

Over the past several decades, considerable resources have been devoted to expanding deceased organ donation in the United States, and that spending has yielded significant and laudable results. The Association for Organ Procurement Organizations reports that approximately 75% of those eligible to become deceased donors do so, and American deceased donor rates are among the highest in the world.

Nevertheless, increasing deceased donation alone can never end the shortage of kidney transplants. The number of deceased donor kidney transplants has remained flat since 2006 while, each year, about seven thousand patients on the waitlist either die or become too sick to transplant. Even if it were possible to transplant 100% of those eligible to become deceased donors, thousands of waitlisted patients would still die for lack of a transplant. Increasing living donation is necessary to end the shortage.

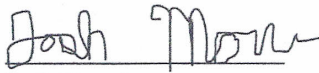
We believe therefore that it is critical to give efforts to increase living donation the same attention and energy that has allowed America's network of deceased transplantation to grow to its current state of maturity. We admire HRSA's initiative in facilitating increased funding for donor travel costs via the National Living Donor Assistance Center and in pushing for stronger donor follow-up standards through UNOS, but we would like to gain a better sense for what else is being done to promote living kidney donation.

To this end, we would like to learn more about HRSA's involvement with living organ donation. Specifically,

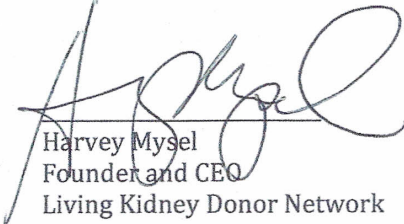
1. What efforts does HRSA currently undertake to increase living organ donation? Does it plan to change or expand these efforts in the future?
2. Currently HRSA has primary responsibility in the federal government for efforts to increase deceased organ donation, does any other federal agency have primary responsibility to increase living organ donation?
3. We understand that for several grant cycles, efforts to increase living organ donation have been excluded from grants funded pursuant to 42 U.S. Code §274f-1(b) (those in the "Social and Behavioral Interventions to Increase Solid Organ Donation", "Public Education Efforts to Increase Solid Organ Donation", and "Clinical Interventions to Increase Organ Procurement" programs). Why were efforts to increase rates of living donation excluded? Does HRSA intend to continue to make similar exclusions in future grants pursuant to this program or other programs to increase organ donation rates?

We would greatly appreciate your help in providing prompt and comprehensive responses to these queries. To facilitate this, we hope to meet and discuss these issues with you prior to receiving your considered answer. Our membership is tremendously grateful for the work HRSA has done in expanding access to transplantation, and we are eager to hear what is and can be done to increase rates of living donation.

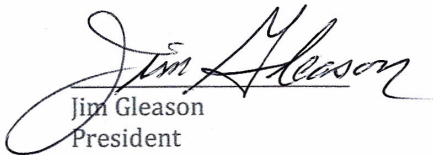
Sincerely,



Josh Morrison  
Co-Executive Director  
WaitList Zero



Harvey Mysel  
Founder and CEO  
Living Kidney Donor Network



Jim Gleason  
President  
Transplant Recipients International Organization



Gary Green  
Executive Director  
American Association for Kidney Patients

Cc

Sylvia Matthews Burwell  
Mary Wakefield  
Cheryl Dammons  
Rita Maldonado