# The Save Lives, Save Money Now! Proposal

# Specifics and Background

Joint project of The Center for Ethical Solutions www.ethical-solutions.org and

The American Living Organ Donor Network www.helplivingdonorssavelives.org

**This proposal could be enacted through Congress**
**or as regulation enacted by HHS without an act of Congress**

Specific Elements:

- **Follow original intent of NOTA and have Medicare help patients in greatest medical need first and according to UNOS current wait list criteria by:**

  **(a) paying expenses of donors willing to give to top match in their region, and**
  **(b) paying the Organ Procurement Organizations (OPOs), which currently match deceased donor organs with recipients, to arrange living matches as well.**

- **Create living donor registry that allows donors at any time after their donation to put themselves AND / OR one relative to the front of the list in the region where the recipient lives (e.g. voucher system, but national. Waiting list points to be determined by UNOS).**
- **Economic analysis that shows this proposal would save Medicare between $17,000 and $30,000 per patient is available upon request from info@alodf.org.**

Background and Details:

The Problem: There is a huge organ shortage. Over 100,000 Americans need kidneys. Too many Americans suffer and die on dialysis or resort to purchasing organs on the black market. Note: A third of all kidney transplants currently done in the United States are through living donation. Even if every American agreed to be a deceased donor there would not be nearly enough cadaver organs to fill the need. There are millions of potential living donors in the United States.

The Solution: Make more living donor organs available in the United States Make it easier for Americans to help fellow Americans. Removing barriers does not mean creating incentives; it means making donation financially possible for those who otherwise can't donate. Financially neutral donation policies alone could reduce the U.S. organ waiting list by as much as 30% in five years.

The Proposal:

(1) Remove the financial **dis**incentives that hinder living donation by establishing a federal benefit to help donors cover the non-medical expenses inherent in any living organ donation. The federal benefit established should only apply to Americans willing to donate to people at the top of the

waiting list in their own transplant region. If patients make it to the top of the transplant waiting list, it is pretty clear they have exhausted all other options for getting an organ. No one wants to wait longer than absolutely necessary because the longer patients are on the list, the more the chance that they will develop health problems that disqualify them from getting a transplant. So, they find donors if at all possible for them to do so on their own. Also, Medicare saves the most money by removing those at the top of the waiting list because those are the patients who are at the highest risk of developing debilitating illnesses that cost Medicare more than providing a transplant. This proposal helps those in greatest need and, in such a manner, that Medicare is certain to save money, not just in the long run, but also in the short run. This policy is not a solve-all solution, but it is an immediate cost-free solution that will go a long way to easing the shortage. This policy could be implemented in conjunction with existing policies and would not prevent the implementation of more comprehensive policies in the future.

Federal Debit Card for Donation Related Expenses and lost wages: Americans who donate an organ to the top willing match at their regional OPO could get a federally issued debit card. A debit card is currently the procedure used by the National Living Donor Assistance Center to pay donors expenses, but qualification for NLDAC assistance is based on the recipient's income, not his or her ranking on the waiting list. It also only covers travel, lodging, and food, not lost wages or other donation related losses/expenses. The National Organ Transplant Act (NOTA) was passed to create a system to help those in greatest medical need regardless of income. The SOTN proposal goes back to the original intent of NOTA. Also note that according to the U.S. Census Bureau, only the top 8% of US earners have enough in discretionary funds in a month to pay the average of $5,000 in out-of-pocket expenses donors pay to donate. Twenty percent of Americans have no savings at all. This means 92% of Americans have to either spend their savings or go into debt to donate. NLDAC only helps the poorest of these Americans and it does so at a financial cost. The SOTN proposal is set up to help more Americans and at a savings to Medicare.

Payment to OPOs: Medicare now pays Organ Procurement Organizations (OPOs) approximately $50,000 to retrieve and deliver a kidney. It currently pays OPOs $0 to include living organ donors in its matching system. If Medicare paid OPOs $20,000 to test and list information for living organ donors, Medicare could pay living organ donors' out-of-pocket nonmedical expenses up to $10,000. Then, Medicare would save $20,000 for every organ transplant done with a living donor rather than a cadaveric organ. Adjustments would have to be made in the calculation to account for hospital costs for living organ donor, but transplants done with cadaveric organs tend to be more expensive anyway because it is harder to get the organ started, they have a higher failure rate than living donor organs, and they last a shorter time than organs from living donors. This is just a hypothetical example. The $50,000 figure comes from the 2013 book *The Global Organ Shortage* by economists Beard, Kaserman, and Osterkamp. Allow charitable organizations to provide non-medical assistance to donors without fear of violating the National Organ Transplant Act (NOTA). The federal benefit would only go to donors willing to give to someone at the top of the waiting list, but charities could help any donor, for example, a linchpin donor for a chain (domino or paired) donation or someone who wants to donate to a family member or friend before that person even goes on dialysis.

(2) Create a living donor registry that allows living donors to move themselves, and/or one relative, to the front of the transplant waiting list. This is a form of voucher system, but its main purpose to assure donors that both they and one relative can receive an organ when needed. This allows donors to both time and place shift their donation to a time when donating is most convenient for them. This provision removes a non-financial **dis**incentive for donation. It allows time-shifting: Some people say they can't donate to a friend or more distant relative because they fear a closer relative may need an organ some day. This registry and its donation vouchers eliminates the need to "save" one's organ in case someone potentially "more important" needs one in the future. It also allows place shifting: Donors could donate where they live and then use one of their vouchers immediately to help a relative get an organ in the region where that relative lives. In this sense, it is another form of paired or swap donation.

**Note that making living organ donation as financially neutral as possible allows for equal access for both donors and recipients. It makes moral and social sense to protect donors who are giving an organ from having to suffer financial losses because of their altruism.**

**ANSWERS TO SOME SPECIFIC QUESTION THAT HAVE COME UP**

1) Why not also cover travel and lodging? The debit card issued under this program could be used to cover any and all costs directly related to the donation. That would include travel and lodging if necessary. But, under this program there would be fewer travel costs donors are required to donate locally. Like with NLDAC, there would need to be regulations that clearly delineate what times of expenses are allowed, e.g. travel, lodging, monthly bills for period where donor is without pay, babysitting, caretaker expenses or losses (unpaid leave), medigap type insurance etc. Anything that is a verifiable donation related expense or loss.

2) How does this program help donors keep their jobs and prevent lost wages? This program compensates donors for lost wages by allowing coverage of bills when donors are on unpaid leave, but it also means less time away from work because it requires donors to donate locally. Less time away from work for testing, the actual donation, and follow-up, means less chance that the donor will lose his or her job because of time away from work. It would be best if donors could be guaranteed not to lose their jobs because of leave taken to donate, but that would require either the passage of laws on the state and federal level. This proposal, as is, can be implemented through a regulatory rule making without Congressional action under NOTA and its amendments as they now stand.

3) Why is the voucher part of the plan important? Donors can time shift or place shift the donation to a convenient time or location. In other words, someone can donate when and where it is convenient and then have their recipient (possibly not even known yet) get an organ when and where it is convenient (or necessary). This means people can do a direct swap — donor donates locally and intended recipient goes to the front of the list in his or her region, or the donor can "pay it forward," but not just for self but also for a relative. So say I have a relative with chronic kidney disease but who does not need a transplant. I can donate now and then put that relative to the front of the list if or when a transplant is needed. One cost advantage here is that the trade is not necessarily one for one. Some donors will give but never ask that a relative be moved to the front of the list or at least not for many years.

4) A big plus of this plan is that it could start helping people right away. IT REQUIRES NO NEW LEGISLATION. HHS could act on its own to implement the plan OR Congress could pass legislation that requires HHS to act

5) This is not an incentives program — no one is being tempted to donate — this is a proposal by donor advocates to do right by donors BIG DIFFERENCE!!! It is cost neutral so that those who already want to donate, are not kept from doing so for financial reasons. There is no direct payment. The proposed debit card could only be used to cover

donation related expenses as they occur. This prevents lump sum pay outs that could be misused. This is also how NLDAC currently works. It is worth keeping in mind, that for many donors, after unpaid leave, the largest expense is travel, but this program discourages expensive long-distance travel by requiring local donations.

6) The restriction to just relatives could be extended to being a relative or friend, particularly if a national registry is used instead of a straight voucher system. The fear is that a voucher system where non-relatives can be helped could result in a market in such vouchers.