The Save Lives, Save Money Now Proposal

Specifics and Background

Stop Organ Trafficking Now! www.StopOTN.org And

The American Living Organ Donor Network www.helplivingdonorssavelives.org

This proposal could be enacted through Congress (specific language available from info@alodf.org) 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 puts donor AND one relative to the front of the list at any time donor chooses.**
- **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 of the 120,000 Americans waiting for transplants need kidneys. Americans resort to purchasing organs on the black market because not enough organs are available at home. 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 at home and increase the penalties for illegal transplant tourism. Removing barriers does not mean creating incentives; it means making donation financially possible for those who otherwise can't donate. Removing barriers to donation 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 by this legislation 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. 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 could be done with a federally issued debit card. A debit card is currently the procedure used by the National Living Donor Assistance Center to pay donors expenses. The problem with NLDAC is that it helps the poorest of the poor – those who can show both they and their recipients earn no more that 300% above the poverty line. 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.

Consider as an example: 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) 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.

3) Create a living donor registry that allows living donors to move themselves, and/or one relative, to the front of the transplant waiting list in their region should they at some later date need an organ themselves or for a relative. This provision removes a non-financial **dis**incentive for donation. 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 eliminates the need to "save" one's organ in case someone very close needs one in the future.

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) No travel and lodging cost or, at least very low costs— people are encouraged to donate locally.

2) Less time away from home and work because donors are donating locally.

3) Donors can time shift the donation to a convenient time. In other words, someone can donate when it is convenient and then have their potential recipient (possibly not even known yet) donate in their own region when they need to.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 our plan is that it could start helping people right away. IT REQUIRES NO NEW LEGISLATION but a Congressional act would require HHS to promulgate regulations.

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!!! Also donors don't just get the money. The $10,000 is a debt card against which costs and lost wages are drawn. This is how NLDAC currently works. It is worth keeping in mind, for donors, the largest costs is travel, and this program makes it so donors don't have to travel — the donate locally.

6) The restriction to just relatives is VERY IMPORTANT — because we don't want to accidentally create a market in the donor benefits this proposal provides.

7) Moving one relative to the front of the list is removing a disincentive. Again and again I hear people say, I would love to donate to my friend or my cousin, but what if my sister or my daughter ends up needing a kidney.