

Based on this view of policy change, it is clear we have more advocacy work ahead of us. So what can we do to advance this enterprise? First, UNOS can be influenced by the same methods that are effective with federal and state government. Proponents of UNOS policy change can write formal letters to the Chair or members of the UNOS Ethics Committee to inform them of concerns with the policy and request policy change. Email letters are also effective. Additionally, we can provide public comment on UNOS policies once they have been reviewed and passed by their Committees, and made available to the public.

If we embark upon this activism, we might encounter some resistance. In the recent past, policy analysts have proffered a host of reasons against engaging in ethical analysis of public policies, including that it is unnecessary, impractical, impossible and undesirable (Amy 1984). Many of these reasons have been unsubstantiated, suggesting that subtle forces have been at play, notably, that ethical discourse is incompatible with the putatively neutral orientation of policy analysts and the work culture of rigid hierarchy and imposed consensus (Amy 1984). Consequently, few policy analysts entered the terrain of ethical analysis, leaving the work for ethicists to do themselves (Amy 1984, 579). Certainly today, bioethics discussions are common and public—consider the recent issues as stem cell research and the Terri Schiavo case. This public face of bioethics may therefore serve to pave the way for greater receptivity by policy makers such as those at UNOS to modify its policies.

I am calling for scholars of organ transplantation to join me in issuing a consensus statement for UNOS and for public dissemination. We can build a coalition or join with other like-minded coalitions. I am not calling for the ASBH membership to take a stand; it is clear that will not happen anytime soon. I am calling for those who agree with this objective to sign up and work toward this

cause. If you are interested in forming or signing such an opinion letter, please email me at: egordo1@Lumc.edu ■

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LifeSharers: Increasing Organ Supply Through Directed Donation

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LifeSharers is a noble and ethical effort to increase the supply of transplantable organs in the United States by expanding the use of directed donation. Restricting the LifeSharers approach to directed donation would decrease the organ supply and cause more Americans to die waiting for transplants.

LIFESHARERS

Professor Zink and her co-authors (2005) devote one paragraph in their paper to LifeSharers. They paint a picture of an organization that exclusively benefits a select community, seeks to exclude non-members, contradicts the concept of equity, manipulates policy to provide its members an

unfair advantage, operates without supervision, and freely discriminates. The truth is far less sinister.

LifeSharers is a grass-roots network of organ donors. Members agree to donate their organs when they die. They also agree to offer their organs first to fellow members, if any member who needs them is a suitable match, before offering them to non-members. This use of directed donation gives people an incentive to donate their organs when they die, by giving them a better chance of getting an organ if they ever need one to live. This incentive increases the number of registered organ donors, and saves lives by making more organs available for transplantation. LifeSharers is a 501(c)(3) non-profit organization staffed by unpaid volunteers.

The authors call LifeSharers an example of “discrimination through directed donation.” LifeSharers members do discriminate, but so does UNOS. What matters is not the existence of discrimination, but whether the basis for it is justified and fair. LifeSharers members discriminate in favor of people who have committed to donate their organs when they die, because that causes more people to donate and makes more organs available to save lives. LifeSharers does not discriminate on the basis of race, color, religion, sex, sexual orientation, national origin, age, physical handicap, health status, marital status, or economic status.

The authors say LifeSharers is an example of “directed donation exclusively benefiting a select community” (8). This is not true. There is nothing “select” about the LifeSharers community. Anyone in the United States can join LifeSharers. Membership is free. And LifeSharers does not exclusively benefit its members. LifeSharers members all agree to share their organs with non-members if no member needs them.

The authors say “LifeSharers seek[s] to exclude non-members” (8). This is not true. We invite everyone to join LifeSharers. We welcome everyone. We turn nobody away. We are actively soliciting new members. I invite everyone reading this to join LifeSharers at <http://www.lifesharers.com>

The authors say “the fundamental problem with LifeSharers is its claim that ‘organs should go first to the people who have agreed to donate their own organs when they die’ and not to people that UNOS determines are most at need” (9). If there were no organ shortage, it would certainly make sense to give organs first to those who need them the most. But there is a shortage, so there are practical and ethical reasons to give organs first to registered organ donors. The practical reason is that it increases the supply of organs, which saves lives. Americans bury or cremate about 20,000 transplantable organs every year, usually for no good reason. That number would go way down if people who weren’t registered organ donors were put at the back of the transplant waiting list. The ethical reason is

equally clear—someone who would throw away his organs rather than save his neighbor’s life has no moral claim to a life-saving organ from his neighbor.

The authors say the LifeSharers philosophy of giving organs first to declared organ donors “contradicts the concept of equity by denying that anyone in need, regardless of their public declaration, should have the opportunity to receive an organ” (9). This is not true. LifeSharers doesn’t deny anyone an opportunity to receive an organ. On the contrary, LifeSharers increases the supply of organs so fewer people will be denied that opportunity. The authors ignore the elephant in the room—the reason many in need don’t get an organ is the shortage of organs.

The authors accuse LifeSharers of “manipulating the policy of directed donation” (9). This is not true. LifeSharers carefully follows the law as it written in every state and at the federal level. And there is absolutely no reason to think it is the “spirit” of any anatomical gift law to stop people from giving their organs to registered organ donors. Besides, how is it “manipulating” to allocate organs in a way designed solely to save more lives?

The authors say LifeSharers provides its members an “unfair advantage” (9). LifeSharers does provide its members an advantage, but it is not an unfair one. LifeSharers doesn’t create unfairness, it corrects it. UNOS currently allocates about 70% of all organs to people who have not agreed to donate their organs when they die. LifeSharers makes the organ allocation system fairer, by helping registered organ donors get their fair share of organs.

The authors say “[i]f providing organ donors preferential status is accepted as an ethical method of organ allocation, then that must be reflected in the UNOS listing policy” (9). It would indeed be wonderful if UNOS decided that organ donors should get preferential status and changed their listing policy accordingly. But UNOS shows no interest in making this common-sense policy change. On the contrary, it has been largely silent on this subject since 1993, when its Ethics Committee recommended “wider societal discussion before considering concrete plans for implementation” of any system that would give an allocation preference to registered organ donors. That is indeed unfortunate. Imagine that UNOS had issued this statement in 1993: “In light of the severe organ shortage, it is not fair to give organs to people who are not registered organ donors. Beginning in 1995, we will not make any organ available to anyone who is not a registered organ donor, unless no registered organ donor needs that organ.” In response to this policy, millions and millions of people would have registered as organ donors. Since 1995, over 56,000 people on the UNOS waiting list have died waiting. Most of those deaths could have been prevented.

The authors say providing organ donors preferential status “is not a topic to be decided by a private organization

that operates according to its own rules without any oversight" (9). Let's put aside the fact that UNOS and LifeSharers are both private organizations. Let's also put aside the fact that LifeSharers operates under the oversight of an advisory group that includes law professors, public policy experts, economics professors, and even the editor of this publication. Let's get right to the heart of the issue—the authors think you shouldn't be able to decide who gets your organs when you die. They say the "only body that is qualified to determine who will receive donated organs in a fair and ethical manner is the medical community acting within well-established allocation criteria." With all due respect to the medical community, when it comes to my organs I am the most qualified body to determine who gets them. I've decided to offer them first to registered organ donors.

The authors say LifeSharers "discriminates against the majority of transplant candidates on the waiting list." (Zink et al., 2005, 9) This is not true. No one on the transplant waiting list is prevented from joining LifeSharers. Anyone can join LifeSharers, regardless of his or her current medical condition.

RESTRICTING DIRECTED DONATION

The authors say directed donation can be "manipulated by individuals whose intent is to move unfairly ahead on the waiting list and by those who wish to discriminate" (9). They propose to limit directed donation to family members because they say it is "the only way to prevent abuse of the system" (9). I have addressed the fairness of moving registered organ donors ahead on the waiting list, so I turn now to other types of discrimination.

The use of directed donation for discriminatory purposes has not been a significant problem in the United States. Even if it was, the authors' proposal is not "the only way" to prevent it. For example, Florida prohibits anatomical gifts restricted on the basis of race, color, religion, sex, national origin, age, physical handicap, health status, marital status, or economic status.

The authors acknowledge their proposal would create problems in cases involving "domestic partners, life-long friends, and common-law marriages" and other "very close" relationships, so they propose "appeals to UNOS" for exemptions to their rule. If adopted, their proposal will kill people. Some will die while the organs they need are held up during the appeals process. More will die after the organs they needed are buried because people chose not to provide "affidavits" and "other documents" to prove to UNOS that their offer of a loved one's organ to a neighbor, friend, or co-worker wasn't motivated by racism, bigotry, or homophobia.

CONCLUSION

LifeSharers uses directed donation to increase the supply of transplantable organs. By restricting directed donation, the authors' proposal would reduce the supply. More people will die waiting for transplants if we make it harder for people to donate their organs to friends, neighbors, or other organ donors. ■

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Non-Family Directed Donation: The Perils of Policy-Making

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Zink et al. (2005) address two important challenges to UNOS's system of organ distribution in the United States: multiple listing and directed donation to nonfam-

ily members. Their thesis is that both multiple listing and nonfamily directed donation should be prohibited because they jeopardize equitable distribution of organs. The