

CHANGING ORGAN ALLOCATION WILL INCREASE ORGAN SUPPLY

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If we change how we allocate organs we will have more organs to allocate.

We should allocate organs first to people who have agreed to donate their own organs when they die. This will cause many more people to register as organ donors and will save thousands of lives every year. Increasing the supply of organs this way is fair and simple, and it can be implemented without legislative action. It is already legal.

Would changing the organ allocation system really increase the supply of organs?

Imagine that the United Network for Organ Sharing (UNOS) made the following announcement tomorrow: “Beginning January 1 of next year, we will make no human organ available for transplantation into any person who is not a registered organ donor. The only exceptions will be directed donations and cases where no registered organ donor matches an organ that is available.” Following the announcement of this policy change, millions and millions of people would register themselves and their children as organ donors. Wouldn’t you, too?

Registering as an organ donor would give you a better chance of getting an organ if you ever needed one. Deciding not to register would reduce your chance. When you consider that more than half of the people on transplant waiting lists in the United States will die before they get a transplant,¹ improving your odds could literally mean the difference between life and death. Agreeing to donate your organs after you die is a small price to pay for a better chance to get an organ if you ever need one to live. Almost everyone would decide to pay that price. The supply of organs would increase, and thousands of lives would be saved every year.

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1. *Assessing Initiatives to Increase Organ Donations: Hearing Before the Subcomm. on Oversight and Investigations of the H. Comm. on Energy and Commerce*, 108th Cong. (2003) (statement of Robert Metzger, M.D., President-Elect, UNOS), available at <http://energycommerce.house.gov/108/Hearings/06032003hearing946/Metzger1498.htm>.

In 2004, about 7,000 deceased organ donors in the United States provided the organs for about 20,000 transplants.² But organs are transplanted from less than half of the eligible deceased donors.³ That means we could obtain 20,000 additional organs every year by changing the organ allocation system. To put that number in perspective, keep in mind that in 2004, 7,305 people were removed from the national transplant waiting list because they died, and 1,663 more were removed because they became too sick to undergo surgery.⁴ With an additional 20,000 organs per year, we could eliminate most of those deaths, reduce the size of the waiting list, and shorten waiting times for people still on the list.

We do not need medical breakthroughs to achieve these results. All we need is behavior change. Only about forty percent of Americans have signed up to donate their organs when they die.⁵ And Americans donate less than half of the organs that could be transplanted.⁶ The rest are buried or cremated. All we need to do is convince people to stop throwing away organs that could save their neighbors' lives. Changing how we allocate organs will produce that behavior change.

The idea of giving registered organ donors an allocation preference is not new. It has been around for more than fifteen years.⁷ Everyone

2. See ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, 2005 OPTN/STR ANNUAL REPORT tbl.1.1, available at http://www.optn.org/AR2005/101_dh.htm (last visited Mar. 1, 2006).

3. Ellen Sheehy et al., *Estimating the Number of Potential Organ Donors in the United States*, 349 NEW ENG. J. MED. 667, 667, 671 (2003).

4. See Organ Procurement and Transplantation Network, Removal Reasons by Year, <http://www.optn.org/latestData/rptData.asp> (last visited Mar. 1, 2006).

5. See People-Press, Bradley Boxes Out Political Center, <http://people-press.org/reports/display.php3?PageID=296> (last visited Mar. 1, 2006) [hereinafter *Bradley Boxes Out*].

6. See Sheehy et al., *supra* note 3, at 671 (stating that “[f]orty-two percent of potential donors (7790 of 18,524) became actual donors” during the period 1997–1999).

7. See LifeSharers, <http://www.lifesharers.org/expertopinion.htm> (last visited Jan. 13, 2006). The LifeSharers website lists various scholarly works supporting the proposition that donated human organs should first be given to people who have agreed to donate their own. See *id.* (citing Steve P. Calandrillo, *Cash for Kidneys? Using Incentives to End America's Organ Shortage*, 13 GEO. MASON L. REV. 69 (2004); Stephen Giles, *An Antidote to the Emerging Two Tier Organ Donation Policy in Canada: The Public Cadaveric Organ Donation Program*, 31 J. MED. ETHICS 188 (2005); Rupert Jarvis, *Join the Club: A Modest Proposal to Increase Availability of Donor Organs*, 21 J. MED. ETHICS 199 (1995); Irvin Kleinman & Frederick H. Lowy, *Ethical Considerations in Living Organ Donation and a New Approach*, 152 ARCHIVES INTERNAL MED. 1484 (1992); Adam J. Kolber, *A Matter of Priority: Transplanting Organs Preferentially to Registered Donors*, 55 RUTGERS L. REV. 671 (2003); Mark S. Nadel & Carolina A. Nadel, *Using Reciprocity to Motivate Organ Donations*, 5 YALE J. HEALTH POL'Y L. & ETHICS 293 (2005); David A. Peters, *A Unified Approach to Organ Donor Recruitment, Organ Procurement, and Distribution*, 3 J.L. & HEALTH 157 (1989); Jonathan Rackoff, *A Reciprocity Obligation to Donate Cadaveric Organs: Re-Visioning Opting In*, 5 ASBH EXCHANGE 1 (2002); Jonathan D. Sackner-Bernstein & Seth Godin, *Increasing Organ Transplantation—Fairly*, 77 TRANSPLANTATION 157 (2004); Richard Schwindt & Aidan Vining, *Proposal for a Mutual Insurance Pool for Transplant*

who has suggested this idea has predicted that it would significantly increase the supply of organs. Some have said it would completely eliminate the waiting list.⁸

But is it fair to allocate organs first to registered organ donors? Yes, in fact it makes the organ allocation system fairer. What is not fair is giving an organ to someone who will not donate his or her own, when there is a registered organ donor who needs it. It is like awarding the lottery jackpot to someone who did not buy a ticket.

Serving registered organ donors first is a simple matter of justice. Justice demands that people who are the same should be treated the same. But the person who has not agreed to donate his or her organs when he or she dies is not the same as the person who has. There is an ethically relevant difference between the two.

Imagine that a heart is available for transplant. Imagine also that two people are a good match for the heart: Mr. Donor, who has committed to donate his organs when he dies, and Mr. Keeper, who has not. Given the shortage of organs, and given that Mr. Keeper's only alternatives to donating his organs are to bury them or burn them, should we treat Mr. Donor and Mr. Keeper as if there is no ethically relevant difference between them? No, Mr. Keeper's failure to donate his organs is a spectacularly selfish act. He would throw away his organs instead of saving the lives of his neighbors—and those are his only available choices. It boggles the mind to suggest that his claim to an organ is ethically the same as Mr. Donor's. Mr. Donor should get that heart, even if Mr. Keeper is sicker or has been waiting longer. Mr. Keeper has no moral claim to an organ. Giving the heart to Mr. Donor serves the cause of justice.

Perhaps more importantly, rewarding Mr. Donor's decision to donate his organs encourages others to do the same. This encouragement saves lives. On the other hand, giving that heart to Mr. Keeper encourages others to delay signing donor cards or to refuse to sign them, and that encouragement lets more people on the transplant waiting list suffer and die.

Organs, 23 J. HEALTH POL. POL'Y & L. 725 (1998); David Steinberg, *An "Opting In" Paradigm for Kidney Transplantation*, 4 AM. J. BIOETHICS (2004); Charles J. Wheelan, *To Get an Organ, Offer to Give One*, WALL ST. J., Dec. 29, 1998).

8. See Moira Flaherty, *New Organ Donation Bill Signed Amid Ethical Debate*, PHYSICIANS FIN. NEWS, June 15, 2004, available at <http://www.lifesharers.org/presscoverage/pfn.mht>. Dr. Robert Sade said, "There are enough cadaveric organs, that is, organs that are medically suitable for transplantation, in people who die each year to completely eliminate the waiting list." *Id.* Dr. Sade is a professor of surgery and director of the Institute for Human Values in Healthcare at the Medical University of South Carolina and a member of the American Medical Association Council on Ethical and Judicial Affairs.

Giving organs first to organ donors encourages people to donate their organs. Giving them to nondonors does not.

But under UNOS's allocation rules, most organs are given to nondonors. In fact, UNOS allocates about sixty percent of all organs to people who have not agreed to donate their own organs when they die.⁹ As long as we allow people who refuse to donate to jump to the front of the waiting list if they need a transplant, we will always have an organ shortage.

Without organ donors there can be no organ transplants. Giving organs first to organ donors produces more organ donors, and that saves more lives. The primary goal of the organ allocation system should be to save as many lives as possible. Other goals should be secondary.

It would be simple for UNOS to change its allocation system to put registered organ donors first. UNOS could simply add a field to its waiting list database which would show whether a potential organ recipient is a registered organ donor. Then when an organ becomes available, instead of offering it first to the highest-ranked person on its match run, UNOS could offer it first to the highest-ranked registered donor.

Putting organ donors first has an important advantage over most other suggestions for increasing the supply of organs. No legislative action is needed to implement it. UNOS already has the authority to give registered organ donors an allocation preference. The UNOS Ethics Committee acknowledged this fact in its 1993 white paper titled "Preferred Status For Organ Donors," in which it wrote: "A trial could be implemented without requiring any alteration in existing legislation"¹⁰ In fact, UNOS already moves live donors up the waiting list if they later need a transplant.¹¹ UNOS can, and should, do the same for people who agree to donate when they die.

Congress has never made tackling the organ shortage a priority, and there is no reason to think it will do so in the foreseeable future. Any-

9. We know this is true because UNOS's organ allocation rules do not consider whether potential recipients are registered organ donors and only about forty percent of Americans are registered organ donors. See *Bradley Boxes Out*, *supra* note 5.

10. JAMES F. BURDICK ET AL., PREFERRED STATUS FOR ORGAN DONORS: A REPORT OF THE UNITED NETWORK FOR ORGAN SHARING ETHICS COMMITTEE (1993), <http://www.unos.org/resources/bioethics.asp?index=5>.

11. See United Network for Organ Sharers, UNOS Organ Distribution Policy, June 24, 2005, § 3.5.11.6, available at http://www.unos.org/PoliciesandBylaws/policies/pdfs/policy_70.pdf. Note that awarding an allocation preference to live kidney donors introduces a nonclinical factor into the organ allocation process. UNOS does not award a similar allocation preference to people who have lost a kidney for other reasons.

one who cares about the more than 90,000¹² people now on the national transplant waiting list should welcome an approach to increasing the organ supply that does not depend on legislative action.

To review, changing the national organ allocation system could save thousands of lives a year and improve the system's fairness. And UNOS has the power to implement this simple change. So, what is UNOS's position on this? It has not really taken one.

The closest UNOS came to adopting this proposed change was in 1993. But its white paper on the subject ultimately stopped short. It only recommended "wider societal discussion before considering concrete plans for implementation" of any system.¹³

UNOS, however, has not led the discussion it recommended. It has been largely silent on the subject since the publication of its white paper twelve years ago. That is unfortunate because over 55,000 people on the UNOS waiting list have died in the last ten years.¹⁴ Most of those deaths could have been prevented.

Fortunately, as individuals we do not need to wait on UNOS to increase the organ supply from the top down. We can attack the problem from the ground up.

You can allocate your own organs. You can offer them first to registered organ donors who will do the same for you. That is the premise behind LifeSharers.

LifeSharers is a grassroots organ donation network. Members agree to donate their organs when they die. Furthermore, they agree to offer their organs first to fellow members—if any member is a suitable match—before offering them to others. Membership is free and open to all at www.lifesharers.org. 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. LifeSharers welcomes everyone and turns no one away. LifeSharers has over 3,600 members, including members in all fifty states and the District of Columbia. Over 300 LifeSharers members are minor children enrolled by their parents. LifeSharers is organized as a 501(c)(3) nonprofit organization. It is staffed by unpaid volunteers, and its operations are funded by tax-deductible charitable contributions.

12. See Organ Procurement and Transplantation Network, <http://www.optn.org> (last visited Jan. 13, 2006).

13. See BURDICK ET AL., *supra* note 10.

14. See ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, 2004 OPTN/SRTR ANNUAL REPORT tbl.1.6, available at http://www.optn.org/AR2004/106_dh.htm (last visited Oct. 8, 2005).

The first question most people ask when they hear about LifeSharers is: “Is it legal?” The answer is yes. LifeSharers is a form of directed donation, which is legal in all fifty states, in the District of Columbia, and under federal law.¹⁵

Every state has adopted the Uniform Anatomical Gift Act. The law in Illinois is typical. It allows donation of body parts to “any specified individual for therapy or transplantation needed by him or her”¹⁶

That is exactly what LifeSharers members do. They carefully follow the law. They donate each of their organs to a specified individual. Specifically, every LifeSharers member says: “[f]or each part of my body donated, I designate as donee that LifeSharers member who is the most suitable match as defined by the criteria in general use at the time of my death.”¹⁷ That means, for example, that I would want my liver to go to the highest-ranked LifeSharers member on UNOS’s match run.

At the federal level, the Organ Procurement and Transplantation Network’s “Final Rule” governs organ allocation policy.¹⁸ It explicitly permits directed donation. The section that regulates how organ allocation policies are to be developed concludes by saying: “Nothing in this section shall prohibit the allocation of an organ to a recipient named by those authorized to make the donation.”¹⁹

Again, LifeSharers carefully follows the law. When a member dies in circumstances that permit recovery of their organs, LifeSharers provides his or her family with the names of individual LifeSharers members, if there are any, who need their organs. The member’s family then directs donation to these named individuals.²⁰

LifeSharers is clearly legal. But can a grassroots effort really reduce the organ shortage in America? Again, the answer is yes. LifeSharers gives Americans a powerful incentive to donate their organs when they die—preferred access to the organs of all LifeSharers members.

15. See Geoff Drushel, *Law & Organs: Directed Organ Donation Is Legal, But Is It Right?*, HEPATITIS MAG., Jan.–Mar. 2005, available at <http://www.hepatitismag.com/storydetail.asp?storyid=133>.

16. See 755 ILL. COMP. STAT. 50/5-10(5) (2004).

17. See LifeSharers.org, How LifeSharers Works, <http://www.lifesharers.org/howitworks.htm> (last visited Jan. 13, 2006) [hereinafter How LifeSharers Works]. In a handful of states, the anatomical gift statutes do not mention donation to “a designated individual.” In those states, LifeSharers members give their organs to fellow members’ surgeons or hospitals, which is permitted. See, e.g., OHIO REV. CODE ANN. § 2108.3 (2003); VA. CODE ANN. § 5242 (2000).

18. The Department of Health and Human Services oversees the operation of the Organ Procurement Transplantation Network, which was established under the National Organ Transplant Act of 1984. See 42 U.S.C. § 274 (2000).

19. Allocation of Organs, 42 C.F.R. § 121.8(h) (2004).

20. How LifeSharers Works, *supra* note 17.

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Simply put, joining LifeSharers gives you a better chance of getting an organ if you ever need one.

As the number of LifeSharers members grows, so does the incentive to join if you are not already a member. Consider, for example, what it will be like when LifeSharers has a million members. You would be crazy not to join. If you elected not to, you would give up preferred access to a pool of one million livers, two million kidneys, one million hearts, two million lungs, and more. That access is a powerful incentive to join LifeSharers. And that incentive can dramatically boost the supply of organs in America.

No LifeSharers member has yet died in circumstances that would have permitted recovery of their organs, but it is just a matter of time. At its current membership level, there is about a seventeen percent chance that organs will be recovered from one or more LifeSharers members in the next twelve months.²¹ When members start getting organs from other members, LifeSharers expects a lot of publicity and a large jump in our membership.

LifeSharers cannot increase the organ supply as fast as UNOS could if it implemented our approach. But I predict LifeSharers will significantly alleviate the organ shortage before any effective legislative action is taken to reduce it.

So, LifeSharers is legal, and it will work. But is it fair? Again, the answer is yes.

I have already covered this issue from the demand side—from the standpoint of the people who need organs. It is also important to look at this issue from the supply side—from the standpoint of the people who donate organs.

If you want to give your organs to other organ donors, is it ethical for a third party to override your wishes and give your organs to someone else? Clearly it is not. But efforts are under way to do exactly that. Some bioethicists have suggested making it illegal for you to direct the donation of your organs to someone who does not have a relationship with you that fits their criteria.²²

Imagine you wanted to give some groceries to a poor person. Then imagine some “experts” tried to force you to give them instead to the United Network for Grocery Sharing, so it could decide who gets them. I expect you would find that offensive. It is even more offen-

21. Assuming 15,000 eligible deceased organ donors per year in a population of 300,000,000 people, the chances of one or more donors from a population the size of LifeSharers's current membership is approximately seventeen percent.

22. See *Transplant Ethics* (PBS television broadcast Sept. 24, 2004) (transcript available at <http://www.pbs.org/wnet/religionandethics/week804/cover.html>); see also Drushel, *supra* note 15.

sive when “experts” say they should decide who gets your organs when you die.

This scheme is also counterproductive because it causes fewer people to donate their organs, and that causes more suffering and more death.

So, what does UNOS have to say about LifeSharers? UNOS says that “[o]ur formal position is that UNOS does not endorse LifeSharers’s approach. But, UNOS does not intervene in directed donation if it is allowed by state law.”²³

UNOS has also said it does not believe LifeSharers has made an “appropriate interpretation of the intent of directed donation” because “the only connection between donor and recipient is that they share membership” in LifeSharers.²⁴ LifeSharers has made no interpretation of any sort. State and federal laws regarding directed donation are clear and plainly written, and LifeSharers members carefully follow them as written. UNOS is the entity interpreting the laws, not LifeSharers.

CONCLUSION

LifeSharers deserves UNOS’s support, not its opposition. Will more Americans donate their organs if UNOS says they cannot donate them to other organ donors, or will fewer donate? The question answers itself. Beyond supporting LifeSharers, UNOS should implement the LifeSharers approach as its own. By doing so, UNOS would increase the supply of organs quicker than LifeSharers will.

Allocating organs first to organ donors can save thousands of lives a year. Nothing could be simpler, nothing could be fairer, and nothing in the law says we cannot make it happen.

23. E-mail from Anne Paschke, Public Relations Manager, UNOS, to David J. Undis, Executive Director of LifeSharers (Feb. 12, 2004, 16:19 EST) (on file with author).

24. Laurie Barclay, *Brokering Organ Transplants on the Internet Raises Ethical Issues*, MEDSCAPE MED. NEWS, Oct. 25, 2004, <http://www.medscape.com/viewarticle/492097>.