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MEDICAL EXAMINER

Organ Failure

Doing battle with the National Kidney Foundation.

By Sally Satel

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Early this summer, the American Medical Association voted to lobby Congress to permit the study of financial incentives for organ donation. With nearly 100,000 people on the national transplant list and 18 dying every day for want of an organ, the AMA resolution to address the organ shortage could not be more timely.

And yet the National Kidney Foundation, the nation's largest advocacy group for people with kidney disease, won't be a reliable ally. The NKF, which has a $32 million annual budget and is to kidney disease what the American Lung Association is to asthma, says it laments that thousands "die while waiting for that 'Gift of Life.' " But instead of locking arms with the AMA, the kidney foundation is poised to sabotage the association's efforts—in keeping with its recent practice of blocking any attempt to explore the possibility of compensating organ donors. Why the stubborn opposition?

When I spoke with Dolph Chianchiano, senior vice president for health policy and research at the NKF, he told me that "compensating donors would cheapen the gift" and lead to fewer people donating overall. As a kidney recipient, I find this hard to fathom. When I was facing years on dialysis, any healthy kidney, paid for or not, would have been precious to me. What about would-be donors? Won't some be more likely to donate their kidneys, or the organs of their family members, because of the prospect of a financial reward? And if others don't benefit in this way themselves, will they really be dissuaded because other people somewhere in the country accepted a form of payment? When asked in a 2005 Gallup poll commissioned by the U.S. Department of Health and Human Services whether "payments" would affect their willingness to give a family member's organs, 19 percent answered "more likely," while 9 percent said "less likely." That margin favors donation. Young people were especially receptive. One-third of 18-to-34-year-olds said the offer of incentives would make them "more likely" to give a family member's organs, compared with 7 percent who said "less likely."

There's additional evidence that the NKF is wrong here. Paying for other products of the body, such as sperm, ova, and wombs (as in maternal surrogacy) is accepted and has not created shortages. When someone donates his or her body to science, medical schools and tissue processing companies cover the costs of cremation or the burial costs of the entire donated body after dissection or experimental use.

The NKF also makes the standard argument that compensation for organs "could propel other countries to sanction an unethical and unjust standard of immense proportions, one in which the wealthy readily obtain organs from the poor." But India, Pakistan, China, the Philippines, Colombia, and other countries already harbor flourishing underground markets. Compensating donors in America won't spur more wealthy patients to travel abroad for organs. It's more likely to show other governments how to conduct a safe and transparent system of exchange under the rule of law. In the end, more people will receive transplants in their home country.

In the end, of course, the effect of compensation on organ supply is a question that only pilot projects can answer. This is what the NKF is trying to suppress. And yet the foundation once understood the need to experiment. In 1993, the NKF endorsed payment of burial expenses for deceased organ donors, a plan passed by the Pennsylvania Legislature. The foundation also supported a House bill in 1999 that would have granted a $10,000

life insurance policy to families with benefits payable upon transplantation of the deceased's organs. At the time, the chairman of NKF's Office of Scientific and Public Policy testified, "We would support at least a pilot study on financial incentives."

It is unclear why the NKF has become less tolerant of incentives as the organ shortage grows more critical with time. But whatever the reason, it forcefully obstructed efforts at reform in 2003—the last time Congress debated bold incentives. That year, House legislation called for noncash rewards, specifying life insurance policies or annuities to the families of the deceased, not an unfettered free market. But the NKF denounced the proposal, railing against "global economists who would import a poor person into this country" to sell an organ. The bill died in committee, partly because of the NKF's efforts. On the Senate side in 2003, the NKF used its clout to kill a provision to study incentives. Afterward, the NKF boasted on its Web site that "a successful advocacy effort by NKF resulted in the removal of the provision." Imagine the American Cancer Society bragging about having derailed an experimental project that might help breast cancer patients—especially when other respected groups were in favor of the measure.

I have long been mystified by the NKF's stalwart opposition to pilot studies. I was spurred to write now about my puzzlement by a recent encounter with the long arm of the foundation. At the end of July, I was invited to speak about the case for donor compensation at a regional transplant conference. Three days later, I was disinvited. Apparently, my chagrined host had not vetted the topic with the local NKF chapter, which was co-sponsoring the event. "I regret that I am having to withdraw my invitation," he wrote me. The co-sponsoring NKF affiliate, he continued, "was very much concerned about repercussions from the New York office, which they think would view the talk as a repudiation of the party line." The NKF similarly tried to stifle a debate on organ incentives at the American Enterprise Institute in 2006.

To be fair, the NKF does some good. It holds scores of fundraising charity events. It offers the public free screening for kidney disease and makes research grants to scientists. The NKF vigorously lobbies Medicare for better reimbursement rates for dialysis care, and, for better or worse (as some nephrologists will tell you), the foundation's guidelines for dialysis set the standard of care for the 380,000 U.S. patients who receive that treatment.

Congress listens to the NKF because it is a major force within the transplant community. But the foundation's recalcitrance on financial incentives for organ donors is hurting the very constituency it purports to serve. Last year, 4,000 dialysis patients died because they could not survive the wait for an organ. When Congress returns in the fall, the AMA will begin its push for demonstration projects on incentives. The NKF will have a chance to return to its earlier common-sense philosophy about rewarding organ donors. Unless it grasps the opportunity, the foundation should not call itself a true advocate for kidney patients.

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