It has been said that, “. . . it takes years to build up trust, and it only takes suspicion, not proof, to destroy it.”\(^1\) The words themselves tell us something about human nature, and unfortunately, are prescient in the context of organ transplants. At a time when a severe shortfall in donation has become emotionally palpable?approximately 18 people die every day while waiting?transplantation survives, imbedded within a fabric of trust. Those who donate their or their loved one?s organs expect that certain precepts will be honored. For example, there is the dead donor rule. If someone has agreed to donate organs after they die, either by whole brain or heart criteria, they must be dead and not merely dying when organs are retrieved. As a result, fiction like Robin Cook’s *Coma* can send a shudder throughout the transplant community. Similarly, in the mid 1990s, when newspapers intimated that cardiac criteria for death may have led to premature organ retrieval, concern was immediate and intense. Americans also respect a ?level playing field.? Remember the public outcry surrounding Mickey Mantle’s liver transplant?allowing the famous or rich to jump ahead of the vulnerable is not the American way. Finally, in an era of quality and safety concerns, the lifesaving process of transplantation should be transparent, compassionate, just, and as safe and quality laden as possible. There are diverse ?patients? involved: donors, recipients, and both families. The public should continue to be very sensitive to potential abuses. This necessary vigilance represents transplantation’s critical check and balance.

A recent *Los Angeles Times* investigative report is most troubling in this regard.\(^2\) The United
Network for Organ Sharing, or UNOS, has been accused of "life-threatening lapses" in oversight that include cover ups of fatal quality gaps, repression of excessive mortality statistics, and frank injustice—costing potential organ recipients their lives. Any single one of these lapses could threaten a tenuous public trust, but in aggregate they could become the worst case scenario.

Since 1985, the Federal Government has contracted with UNOS, at approximately $25 million per year, to supervise and regulate the transplant enterprise in the United States. However, specific examples of UNOS' alleged failures should suffice to raise serious capability questions. Throughout a twenty-one year history, without outside pressure, UNOS has repeatedly avoided program closure. As one example, in 2002, potentially lethal issues in one Nevada program merely resulted in an investigation 4 years after discovery! Mortality throughout those 4 years continued to be unacceptably high. Another transplant program in Wisconsin defied UNOS' efforts to close its lung transplant program since it was not performing any transplants. The downside was that children on that waiting list were excluded from life saving surgery elsewhere. The program in question refused to comply with the UNOS judgment! So as a compromise, that program was placed on "confidential probation." Review by UNOS of a program in California demonstrated that twice as many people died awaiting transplants than those dying in the group receiving organs. These data were the opposite of comparable programs in the region. In reality, UNOS investigated that program only after the Los Angeles Times published the poor outcomes. Finally, in Pennsylvania, a transplant program misrepresented patients' conditions—reporting that they were sicker than they really were—in order to get unjust priority for available organs. Surely this was a problem that could be remedied? Unfortunately not, the misrepresentation continued for 4 more years and was not made public. Some of the aforementioned 18 deaths a day on waiting lists were a result. Similar criticism of the early mortality in adult living related liver transplants (donor and recipient) is contingent on a lack of accountability. Programs were allowed to proceed with a then experimental procedure indifferent to outcome.

What are the reasons for the ethical shortfall? UNOS is correct when they say that they are not a "police force." They are not able to be police because they represent the transplant community, not patients. Three transplant programs up for review have members on UNOS' Board. Despite the obvious bias, Federal officials are happy with the UNOS status quo. If the present situation is not rectified, persons donating, as well as those on the waiting list, are going to suffer and die. The public response may irreparably endanger the future of a lifesaving treatment.

It is time that UNOS ensures the accountability of the entire transplant community. There are many motivated and gifted individuals who have received a transplant, donated an organ, or are family or friends of either a donor or recipient. They have to take the reins of UNOS and change its composition and motivation. Only they can guarantee a just and transparent process before public trust erodes enough to stifle the "Gift of Life."

References


Ornstein and Weber.

Podcast Episode:
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