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ORGAN TRANSPLANTS

Saving Lives: Making the Case to Test Financial Incentives
to Increase the Deceased Donor Supply

SUMMARY

- The present deceased organ supply covers half of the yearly transplant needs.
- The total estimated organ availability will barely cover the yearly organ additions to the waiting list.
- It is estimated that only 50% of the organs available are recovered. We should consider it a national societal failure that half of the organs available are buried with the deceased while 16 people on the waiting list die every day due to the lack of organs for transplantation.
- Educational and other initiatives so far have failed to stop and, much less, reverse the negative trend of decreased organ donations.
- The key of this Proposal is to give the individual the responsibility of making the organ donation decision (Donor Authorization).
- The financial incentive is to induce millions of individuals to sign the witnessed form, when offered with the tax returns and the driver's license applications.
- This proposal is:
  - Morally acceptable because the distribution of organs is not altered and the compensation goes to the beneficiary after the patient's death
  - Ethical because there is no coercion to sign the donation document
  - Egalitarian because it gives every individual, regardless of their economical status, the opportunity to bequeath a compensation to their family
  - Economically sound because each deceased donor saves the insurers (Medicare or private insurance) between $400,000 and $800,000
- The cost of such compensation to Medicare and private payers will be over-compensated by eliminating the annual medical cost incurred to maintain these high resource-consuming patients on the waiting list.

- The value of saving or improving the quality of life of patients in kidney dialysis or heart and liver failure, although very hard to quantify, is at the essence of American values.

- Congress should pass legislation allowing the individual decision to be binding and trials of financial incentives to facilitate their massive enrollment.

OVERVIEW

In the past three decades, organ transplantation has evolved more rapidly than any other medical technology. What was once an experimental procedure that offered uncertain results at enormous expense is now the standard of care. More than 90% of organ transplants are successful. Organ transplant recipients lead normal lives. A liver transplant recipient recently won a silver medal in the Olympics, and a kidney recipient plays in the National Basketball Association. Bob Wolfe reported in the New England Journal of Medicine in 1999 that life expectancy is approximately double following a kidney transplant compared to chronic dialysis. In fact, chronic dialysis has a higher mortality rate than the majority of cancers, while the majority of kidney transplant recipients will live at least 15 years. Due to the higher incidence of kidney failure in the African-American population, the current reliance on dialysis, rather than transplantation, disproportionately affects this segment of society.

Kidney transplants represent 60% of all the organ transplants performed in the USA. The alternative to kidney transplantation is chronic dialysis, a phenomenally expensive technology. Since the vast majority of kidney transplant recipients survive without dialysis, each kidney transplant results in substantial savings of health-care dollars. After deducting the costs of the transplants, according to A.J. Matas, MD, from the U. of Minnesota, each kidney transplant generates savings of between $200,000 to $400,000 for the payers of dialysis and medical treatment. This analysis was confirmed in a separate study by Zachary Dyckman, PhD, using different methodology. Since Medicare pays 60% of these bills, the taxpayer will be the major economic beneficiary.

Over 6,000 patients are dying each year for lack of an organ transplant. There are ethical, economical, and available solutions that the current law prohibits the medical community from testing. Patients are dying not from limited medical knowledge about how to transplant or care for these patients, not for lack of doctors and nurses, not for lack of insurance, and not for dangerous lifestyles. In America thousands of patients are dying each year because organs from recently dead patients are going to the ground with the deceased. This proposal is about testing in a limited, ethical, and professional manner whether or not financial incentives would offer a tool to save many of these lives each year.

The continuous growth of the Organ Transplant Waiting List has reached 82,731 as of 6/30/01. This is the result of a yearly deficit of organs available over the number of patients requiring organ transplants. This deficit increased 18,821 in 2000, at which time 22,917 organs were transplanted. Is this yearly deficit due to lack of available organs or inadequate organ donations and recovery?

To cover the needs of the 41,738 organ recipients added last year to the waiting list, we would have needed approximately 16,000 deceased donors for the 24,000 patients requiring a kidney (1.5 per donor) or a combination of a complementary number of living donors and about 9,500 brain-dead donors for heart, liver, lungs, etc., at the present rate of deceased organs per donor recovery.

On average, each deceased organ donor provides 1.55 kidneys, 0.75 livers, 0.38 hearts, 0.25 lungs, and 0.23 pancreas. With adequate organizational changes, the efficient use of these donated organs should be much higher.

That year there were 5,984 deceased donors and 5,665 living donors. The new entrances on the waiting list would have required 2½ times the number of deceased donations and double the number of living donors.

Despite not having good, well-documented studies about organ availability, the number of medically suitable organ donors has been very conservatively estimated to be between 12,000 and 15,000 a year, which could go up to 18,000 or more with non-beating heart candidates. Recovery of non-beating heart donors is a rare but growing procedure which may offer additional donor opportunities.

ORIGIN OF DONORS

Contrary to the public perception, motor vehicle accidents contributed only 23% of the donors, while 51.2% were due to natural and other causes. There are a lot of suitable donors available to compensate for the increased survival of victims of motor vehicle accidents.

DISTRIBUTION

UNOS has divided the country into 11 regions. #5 is the largest with 42,849,428 inhabitants and 35 transplant centers that transplanted 0.0073% of the population. #1 is the smallest area with 13,342,454 inhabitants and 15 transplant centers that transplanted 0.0022% of the population. Because of better results, the indications are broader. The more transplant centers per region, the more transplants are made and there is the most demand of organs for the population base. Recent studies seem to suggest better long-term transplant results in

patients who were never on dialysis before. If organs were available in unlimited numbers, the indications for kidney transplants would markedly increase and proportionally decrease the number of patients on dialysis. It should be noted that dialysis patients have a much lower quality of life and higher risk of death than do comparable patients with a transplant.

ETHNIC BACKGROUND

The donations by ethnicity follow quite closely the proportion of the general population; 70% were White donors (75.1% of the population), African-American 11.3% (12.3% of the pop.), Hispanic 10.6% (12.5% of the pop.), and Asian 2.2% (3.6% of the pop.).

Akinlolu Ojo, MD, using the death data from the National Center for Health Statistics Mortality Detail File and the donor information in the Scientific Registry of Transplant Recipients, estimates that the African-American community can do much more to alleviate their organ needs. He states that for each 1,000 White potential donors' evaluable deaths from gunshot and stab wounds, 800 will become organ donors. Comparably, only 200 of 1,000 African-Americans in the same situation will become donors. Of 1,000 patients dying of head trauma, 800 Whites will become donors and 600 African-Americans will do so. Of 1,000 who die from motor vehicle accidents, 340 Whites donate their organs and only 130 African-Americans will become donors.

AGE

81.2% of the kidney donors come from the 18 to 64 age range, 83.4% of the livers from the 11 to 64 age range, and 81.5% of the hearts from the 11 to 49 age range.

A popular misconception is that age limits the number of donors. The present trend is to accept older donors because they are extending the life of the transplant recipients. For the older patients, the healthy new organ of their own age prolongs their life quality and expectancy to justify the procedure. Despite still being rare, the oldest donor for kidney was 83 years old, 85 for liver, and 73 for heart.

It is interesting to note that there are 8,216 patients over 65 years of age awaiting an organ. The wastage of these "extended donor organs" is 4 times the wastage of younger, recently dead organs.

WAITING LIST

By gender, the waiting list for hearts is 77.6% male and 22.4% female.

Whites are 55% of the waiting list for kidneys and 75% of the population, African-Americans 35% for 12.3% of the population, Hispanics 12% for 12.5% of the population, and Asians 4% for 3.6% of the population.

The reason for the disparity between the African-American population percentage and the higher waiting list percentage (35%) is the very high incidence of hypertension and diabetes among African-Americans that, despite being 12.3% of the population, receives 22.5% of the kidney transplants.

African-Americans have four times the rate of kidney failure, even at same blood pressures levels, as do White Americans and, for that reason, there is a disproportionately higher need of kidney transplants. Genetic, socio-economic conditions, access to the health care system, types of medications, treatment compliance, etc., should be researched in depth to find better and fairer approaches to this problem.

DISCUSSION

#1 - Most authors agree that 100% recovery of presently estimated organ donors will barely cover the yearly organ needs.

There is a wide gap between the organs required yearly for transplantation and the organs donated; approximately 2½ times the deceased organs and 2 times the living donors. This has created a very large backlog of patients that, with the present approach, will never receive a transplant.

#2 - According to the present estimates, the total availability of potential deceased donors will barely, if at all, cover the yearly needs for organ donors. Organizations like AOPO (Association of Organ Procurement Organizations) are working to establish a scientific base to determine and access the true number of available donors.

A bill was introduced in the 107th Congress Senate, S. 1062, by Mr. Durbin, Mr. Collins, Mr. Biden, Mrs. Clinton, Mr. Feingold, Mrs. Feinstein, Mr. Johnson, and Mr. Inouye on June 19, 2001: “To amend the Public Health Service Act to promote organ donation and facilitate interstate linkage and 24-hour access to state donor registries, and for other purposes."

H.R. 955 introduced in the 107th Congress House of Representatives on March 8, 2001 by Mr. Inslee: "To amend the Public Health Service Act to provide for a National Living Organ Donor Registry," which was referred to the Committee on Energy and Commerce.

H.R. 953 introduced in the 107th Congress House of Representatives by Messrs. Inslee, Spence and Cantor on March 8, 2001: "To amend the Public Health Service Act to authorize grants to carry out programs to improve recovery rates for organs in eligible hospitals." In section 2, a program of grants is established to increase the number of Hospital Organ Donation Coordinators.

#3 - New, innovative and intensive campaigns will have to be conducted to secure as close as 100% of the potential donors just to cover the yearly needs.

A bill was introduced in the Senate, S. 788, by Mr. Schumer: "To amend the Public Health Service Act to establish a National Organ and Tissue Donor Registry that works in conjunction with state organ and tissue donor registries to create a public-private partnership to launch an aggressive outreach and education campaign about organ and tissue donation and the registry and other purposes." It was referred to the Committee on Health, Education, Labor and Pensions.

A bill was introduced by Mr. Frist, Mr. DeWine, Mr. Durbin, Mrs. Murray and Mr. Thurmond to the 107th Congress Senate, S. 325, on February 14, 2001: "To establish a Congressional commemorative medal for organ donors and their families."

#4 - The public perception that only young accident victims are potential donors has to be changed in view of the extended use of older donors, even in the 8th decade. Older people in general seem to handle death-related emotional problems associated with organ donation requests better than the younger ones.

#5 - It is apparent that the more organs become available, the more likely indications will liberalize and increase the organ demands.

#6 - Every ethnic group contributes approximately the same proportional number of organs according to the populations' percentage, but not according to the qualified organ availability (A. Ojo). African-Americans would have to increase the number of available organ donations to help close the gap of their unusually higher needs for kidney transplants.

African-Americans have such a high rate of kidney failure compared to Whites that despite receiving a larger number of transplants, they have many more patients on the waiting list than their proportions in the general population.

Measures to improve access to prevention and compliance of treatment of hypertension and diabetes before they become terminal renal disease have to be strongly initiated on a national scale to decrease the number of recipients in this high-risk group of the population.

A bill was introduced in the 107th Congress House of Representatives, H.R. 1218, by Mr. Baca on March 27, 2001: "To provide for an African-American Health Initiative under which demonstration projects conduct targeted health campaigns directed at high-risk African-American populations."

#7 - There are more than three times the number of males than females on the heart transplant waiting list. Research into preventive heart failure measures and alternatives to heart transplants should be strongly promoted.

#8 - Several initiatives have been introduced in Congress to add a financial incentive to organ donations.

107th Congress, H.R. 2090, in the House of Representatives on June 6, 2001: Representative Smith of New Jersey introduced a bill to amend the tax code to allow a $2,500 deduction to the designated person of an organ donor. It was referred to the Committee on Ways and Means.

107th Congress, H.R. 1872, in the House of Representatives on May 16, 2001 by Mr. Hansen: "To amend the Internal Revenue Code of 1986 to allow a refundable credit to individuals who donate their organs at death." This bill will allow a $10,000 credit for the taxes of the individual who has signed a valid donor card and became a donor of at least one organ at the time of death.

An Act of Congress, H.R. 624, in the House of Representatives was passed on March 7, 2001, allowing payments for travel expenses for living organ donors.

In the 106th Congress, Rep. Greenwood presented at a hearing before the Subcommittee on Health and Environment of the Committee on Commerce of the House of Representatives – April 15, 1999, Project Organ Donor. Serial No. 06-14, Project Organ Donor consists of a $10,000 insurance-like policy payment to a person or entity designated by the donor at the time of signing a legally binding, national document upon successfully transplanting one or more of his/her organs at the time of death.

#9 - H.R. 5224 introduced in the 107th Congress House of Representatives by Messrs. Greenwood, Frost, McGovern, Miller and Mrs. Christensen to fund demonstration projects for the purpose of increasing organs donated for human transplantation, including financial incentives.

#10 - H.R. 399 introduced in the 108th Congress House of Representatives by Messrs. Bilirakis, Brown, Tauzin, Dingell, Upton, Waxman, Burr, Deutsch, Wynn and Pallone providing for the payment of travel and subsistence expenses incurred by individuals toward making living donations of their organs.

#11 - S. 572 introduced in the 108th Congress Senate by Mr. Frist to establish a congressional commemorative medal for organ donors and their families.

#12 - S. 573 introduced in the 108th Congress Senate by Messrs. Frist, Dodd and Enzi to amend the Public Health Service Act to promote organ donation, and for other purposes. This bill provides guidelines for Demonstration Projects, Education and Public Awareness.

CONCLUSIONS

If even 50% of what are considered lost suitable donors were recovered (approximately 3,000 donors), 9,500 organs could be recovered under the current, rather conservative estimates of organs per donor (3.2). This number of recovered organs would potentially save many patients, improve the quality of life for a great number of patients, and remove a lot of pressure on people to become living organ donors.

Recognizing that to request an organ donation at the time of the donor's death is the worst time emotionally to obtain an authorization from the bereaved family, the population in general, and legislators in particular, are increasingly becoming aware that the act of donation should be shifted to the true donor to make his/her altruistic decision ahead of time in a considered, calculated manner, as with any other important event in his/her life (Donor Authorization).

To be effective, the donor authorizations should be signed by millions of individuals. Several initiatives, including financial incentives of $10,000 as a tax credit or as an insurance-like policy to be received by the designated beneficiary upon the successful transplantation of his/her organs at the time of the donor's death, have been introduced in Congress. The objective of the significant benefit is to make the citizens focus on the document offered to them with the tax return form or the driver's license application.

Congress should debate and pass legislation to make legally binding the donors' decisions about the destiny of their organs in the case of brain death (Donor Authorization). For the Donor Authorization to be effective, the enrollment should be massive and, for that purpose, Congress should authorize the HHS Secretary to start trials of financial incentives to increase organ donations.

This bill could include items proposed in bills previously introduced in Congress, like:

#1 – Create a national organ registry with 24-hour access, 7 days a week, 365 days a year, to keep nationally-agreed-upon, legally-binding documents signed by the donors. A form soliciting organ donation should be offered to everybody between 18 and 90 years of age when submitting the tax return, obtaining a driver's license, applying for social security, entering military service, filling out employment forms, etc.

#2 – Create a significant economic incentive in the form of a tax credit or insurance-like policy to promote donations at the time of requesting the potential donor to sign the legal, witnessed document.

#3 – Encourage transplant organizations to seek ways to increase the average number of organs used per donor from the present 3.6 x donor.

#4 – Fund effective preventive and alternative programs to decrease the need of transplants for the higher risk groups, i.e., African-American hypertension and diabetes control and congestive heart failure circulatory support, etc., which are less expensive than the cost of the medical care to maintain these patients on the waiting list each year.

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PROPOSAL

The subject of increasing organ donations is very close to my heart, and I am passionate about doing something to improve it. While years of deliberations have taken place, 16 patients die every day waiting for available organs that our system fails to have donated. In their names, we should act now to correct this tragic failure.

The key to our proposal is to shift the decision to the donor (Donor Authorization).

I have served on the board of a hospital that is the nation's second largest donor of deceased organs and yet still misses a large number of possible donors. Our experience is that when the patient's desires are known, almost always the organ donation follows. In the best American tradition, it is right that individuals make provisions when they are of able mind and body for what is to be done with their organs in the event of brain death. This notion has finally taken hold in the transplant communities around the country and is now favored by many professional and family associations.

In July 2003, sponsored by Rep. John Gleason, the Michigan Legislature passed Public Act 76: Organ Donations; Prohibiting Veto by Family Members. It's an essential first step, but to be successful and access the 50% of donor candidates that we are now missing, it will require the massive enrollment of millions of citizens. Educational campaigns, advertisements, enrollment drives, and all the methods tried up to now have had disappointing results. The almost flat rate of Deceased Organ Donations of the past few years confirms that only 14% of the individuals polled believe they will contribute to an increase in donations.

For these reasons and based upon "Project Organ Donor" of Gene Epstein and Al Boessmann, DVM, we propose to offer a $10,000 free term insurance-like benefit or a similar tax credit to induce individuals to sign a witnessed document that would be offered with the tax return form or driver's license application. These two activities reach almost 100% of the U.S. population at one time or another in their lives.

Why do we offer a $10,000 after-death compensation to be left to the beneficiary of their generosity? Because it is an amount significant enough to make the individuals focus on the document offered, and because this amount has been mentioned to compensate for organ donations in other legislative initiatives, like paying for funeral expenses or hospital bills up to that amount.

To address the valid concerns of minorities whether in an emergency they would be given adequate terminal care if an insurance or tax credit exists, the organ donor document can be accessed only when the patient has been declared brain dead and the family has been notified.

Each kidney transplanted alone saves between $200,000 and $400,000 to the insurers who are presently paying to keep these patients alive on the waiting list. Medicare, which pays 60% of these bills, would decrease its budget by billions of dollars.

This proposal respects the autonomy of the individual, has been accepted by most religions and ethical organizations, addresses the concern of minorities about their possible terminal care, empowers the poorer members of society to bequeath to their families the societal recognition of their generosity, and it makes economic sense, saving billions of dollars to the present payers.

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