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ORGAN TRANSPLANT TRUST FUND

HEARING

BEFORE THE

SUBCOMMITTEE ON
TAXATION AND DEBT MANAGEMENT

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

ON

S. 2409

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TUESDAY, SEPTEMBER 20, 1988

U.S. SENATE,
SUBCOMMITTEE ON TAXATION AND DEBT MANAGEMENT,
COMMITTEE ON FINANCE,
Washington, DC

The hearing was convened, pursuant to notice, at 10:07 a.m. in Room SD-215, Dirksen Senate Office Building, Hon. Max Baucus (chairman of the subcommittee) presiding.

Present: Senators Baucus and Chafee.

[A description of S. 2409 by the Joint Committee on Taxation appears in the appendix.]

[The press release announcing the hearing follows:]

[Press Release No. H-37, September 15, 1988]

FINANCE SUBCOMMITTEE ON TAXATION AND DEBT MANAGEMENT ANNOUNCES HEARING ON ORGAN TRANSPLANT TRUST FUND

WASHINGTON, DC—Senator Max Baucus (D., Montana), Chairman of the Senate Finance Subcommittee on Taxation and Debt Management, announced Thursday that the Subcommittee will hold a hearing on S. 2409, the Cooperative Organ Transplant Contributions Act of 1988. The bill, sponsored by Senator Dale Bumpers (D., Arkansas), would allow taxpayers entitled to an income tax refund to designate all or any portion of their refund as a contribution to the National Organ Transplant Trust Fund. The bill would establish the trust fund within the United States Treasury.

The hearing is scheduled for *Tuesday, September 20, 1988 at 10 a.m.* in Room SD-215 of the Dirksen Senate Office Building.

"In recent years, medical research has made organ transplants a reality for many patients. However, the cost of an organ transplant operation can vary from burdensome to prohibitive," Senator Baucus said. "The Subcommittee will hear testimony on the feasibility of an organ transplant trust fund to help pay for such operations."

OPENING STATEMENT OF HON. MAX BAUCUS, A U.S. SENATOR FROM MONTANA, CHAIRMAN OF THE SUBCOMMITTEE

Senator BAUCUS. The hearing will come to order.

Good morning, everyone. Welcome to this morning's hearing. Today the subcommittee will consider legislation introduced by Senator Bumpers from Arkansas to provide a tax return check-off system for financing the federal organ transplant trust fund.

Recent advances in medical science have made organ transplants an acceptable medical treatment for many patients, in fact a necessary medical treatment for many patients. I expect that today's witnesses will give several examples of why that is true.

However, the cost of organ transplants is very expensive; in fact, it is prohibitive to many patients, and it is very, very difficult therefore for those patients to receive the medical treatment that they deserve—in fact, must have if, in some cases, they are to continue to live.

Senator Bumpers has developed a proposal to help address that problem, that is, help make organ transplants more available to those people in America who are unable otherwise to pay for the transplants.

Senator, we are honored to have you here. Why don't you explain your proposal and the reasons why you think it should become law?

STATEMENT OF HON. DALE BUMPERS, A U.S. SENATOR FROM ARKANSAS

Senator Bumpers. Mr. Chairman, first of all, let me thank you for your generosity in committing your time to chair this hearing today. As you know, I have labored for some time on this proposal; and it is an idea, I think, whose time has come.

You are very kind to take the time to hear not just my presentation, which will be pale compared to the statements of the two transplant surgeons who are here today and the statement of the Maryland couple who have gone through the ordeal of raising the money for a heart transplant.

I think all of this testimony is going to be poignant, interesting, and instructive.

With your permission, Mr. Chairman, I would like to submit my formal statement for the record and simply summarize the bill and what it does.

Senator Baucus. Your statement, Senator, and those of all the witnesses will be put in the record in full.

Senator Bumpers. Tthe reason I got interested in this issue was because of a plea I received several years ago from a woman in southwest Arkansas who had a 50-year-old daughter in need of a liver transplant. The cost of the transplant was $150,000. Her daughter was a professor at Jackson State University in Jackson, Tennessee, a very bright woman who had been, because of her medical condition, on Medicare disability.

Now, Dr. Starzl and others will perhaps testify about what the age ought to be for liver transplants and so on; but it is my understanding that age is certainly a determining factor as to who ought to get a transplant.

She was a borderline candidate for a transplant at the age of 50, but the point is she simply couldn't raise the money. I foolishly believed that perhaps I could very quickly get the Medicare laws changed to provide that people who were on Medicare would be eligible for liver transplants.

At that time and to this day, Medicare covers liver transplants only for beneficiaries under age 18. In fact, that means Medicare almost never pays for a liver transplant. I proposed an amendment that would have lifted that age limit on liver transplants. I believed the amendment would have resulted in Medicare paying for only about 6 to 10 liver transplants annually.

I came within three votes of getting that amendment approved; and I will never forget a Senator came up to me just before the vote—and he finally voted with me after some persuasion—you know, we only have 15 minutes to change people's minds over there—and he said: Dale, this is micromanagement at its worst. And I said: You know, if you were Mrs. McKelvey in Hope, Arkansas; with a 50-year-old daughter who is going to die unless you can come up with $150,000, you wouldn't give a damn whether it was micro, macro, or any other kind of management. All you want is help.

Now, here we are in this great Nation of ours, advanced technologically to the point that we can transplant virtually every organ in the body. We started off with the corneas; we went from there to kidneys.

I am happy to say that University of Arkansas was one of the leaders in research in kidney transplants, and we still have a tremendous end-stage renal disease program there. But here we have this technology, and yet we have this crying need for money.

Mr. Chairman, you and I know all too well that if we tried to take this money out of the Treasury, you would hear all the normal howls about the budget deficit. So, we have two problems. Number one is donors, the availability of organs; and we are making great strides in efforts to match people who are suitable donors with suitable donees.

That is one part of the problem, and this bill does not address that.

The second part of the problem is the tremendous cost and the number of people who need transplants but simply can't afford them. Just listen to this, Mr. Chairman.

Liver transplants cost $180,000 to $400,000. Heart transplants cost $80,000 to $140,000. And heart/lung transplants cost $130,000 to $200,000. Now, if you are on Medicare today, you can get a transplant for a kidney, and Medicare will pay for it. Medicare will also pay for heart transplants and liver transplants if you are under age 18, but if you happen to be above 18, it doesn't pay for a liver.

In Medicaid, we are all over the lot; the States have many different programs for transplants. You saw just recently where Oregon, which had a very fine, advanced transplant program in the Medicaid program, opted to quit funding all transplants, in order to increase funding for—neonatal or prenatal care—where they felt they could serve so many more people.

One of the points I want to make on that is we should not, in a great, powerful, rich nation like this, have to make those kinds of very unpleasant choices. We have 37 million people in this country, Mr. Chairman, who are uninsured—who simply have no health insurance. Many of them work but simply aren't covered in the workplace, and many others fall through the Medicaid cracks.

As we have cut back on the Medicaid funds on the Federal level, States have had to change their Medicaid qualifications and criteria in order to serve as many people as they could with the limited funds available to them.

Now, here is another set of statistics on the number of people in this country who are waiting. First, let me give you the number of transplants that occurred last year. We had 11,000 kidney transplants last year. While it is still major and serious surgery, you can see that kidney transplants are rapidly becoming rather routine.

We have 1,500 heart transplants in 1987, and others will tell you how many of those are now living. We have a gentleman who is here this morning with his wife, who will testify, who is four years out from his heart transplant.

We had 1,200 liver transplants last year, and we have had nearly 3,000 liver transplants since the first one was done.

Now, here is the waiting list that makes the urgency of this proposition so clear. We have 13,000 people awaiting kidney transplants.

We have 900 people awaiting heart transplants, 200 awaiting heart/lung transplants, 500 awaiting liver transplants, and 200 awaiting pancreas transplants. Some of them are awaiting a suitable donor, but some of them are waiting simply because they don't have the money.

Mr. Chairman, I am addressing this problem in the only way I know to do it, given the budget constraints we are operating under. My bill would give the American people an opportunity to contribute some amount of money through their tax returns. It is not a deductible contribution.

Under this bill, if you fill out your tax return and you decide to check off $5, you must insert $5 for that; and it is not a deduction. It is something you must give.

As I said in the opening part of my testimony, Mr. Chairman, the American people deplore this situation as much as I do, and this bill gives them an opportunity to participate in a very small way; it allows American to channel their generosity into a trust fund which will then go back to the States in the exact amount that it comes from that State.

Somebody might say: Well, Mississippi and Arkansas are fairly poor States; they are not going to contribute as much; and New York, of course, will contribute more. That isn't necessarily true, but I think the main reason for structuring the bill in this way is that people will more willingly contribute if they know that the money is coming back home.

Then, we will allow the States to develop their own programs and report to the Secretary of Health and Human Services each year—on the criteria they've established, how they are handling the trust funds, how successful the program has been, and so on.

Mr. Chairman, one of the most deplorable things about these budget deficits is that we have now a tremendous surge of unmet needs in this country. You and I both know that in the good old days, the solution to this problem would have been very simple. We would simply have passed a $100 million appropriation and given it to Medicaid or to whomever we needed to give it to make sure that no person in this country ever died for want of money. And yet, that is the precisely the situation that exists.

When it comes to bake sales and pie sales and people holding out their tin cups pleading for money, it is so much easier to raise that money for a young child who is photogenic, appealing, and attractive than it is to somebody who is a little older and may not be so attractive. We need to eliminate that problem also.

Mr. Chairman, I think that about covers all the facets of the bill, the background and so on. If you have any questions, I will be delighted to try to answer them.

[The prepared statement of Senator Bumpers appears in the appendix.]

Senator BAUCUS. Thank you very much, Senator.

Your testimony reminds me of a point that I think indicates the nature of a similar problem we have in our country. Namely, we Americans spend more than 11 percent—close to 12 percent—of our gross national product on health. That is much higher than any other country in the world; and yet, our infant mortality rate is so high that I think we rank 18th in the world.

There are 17 other countries that spend less as a percent of GNP on health care and that have lower infant mortality rates than we do. The reason for the discrepancy probably is that there are a lot of Americans who are better off, and, in those parts of the country, the infant mortality rate is lower; but in those parts of the country where Americans are less well off we probably tend to find a higher infant mortality rate.

Certainly, I would guess this type of problem is also true with organ transplants. Wealthy Americans and those who have health coverage probably are more likely to be able to afford an organ transplant, whereas Americans who don't have health insurance, who are on Medicaid, or who are on Medicare disability cannot afford the operation.

So, you are addressing a very basic problem that has to be addressed. The question I have is: What do other countries do? How do they address the problem of not only the availability, but the cost of organ transplants?

It is a very basic problem that is going to have to be addressed.

Senator BUMPERS. I might comment that Betty Bumpers is not only Secretary of Peace; she is also Secretary of the Childhood Immunizations. As you know, when the Carters were in town during his term as President, she convinced the President to turn her loose on child immunizations; and we went from about 88 percent immunization levels to about 97 percent.

Unhappily, since that happy day in 1979 when we announced that, immunization levels have been declining among some groups. She is speaking at Children's Hospital in Washington today at a luncheon about this problem and how to solve it.

As you pointed out, in 1955 we were sixth in the world in infant mortality; today we are 18th. There is just a simple point to be made. That is, we go at problems on a crash basis when we have an epidemic; and then, we forget them; turn our backs on them.

Senator BAUCUS. Do you have any estimates as to how much revenue would be raised under this proposal?

Senator BUMPERS. We just took at guess at $50 to $80 million, and that is probably enough to fund this thing. We think it will be.

Senator BAUCUS. And how would that be allocated among the States?

Senator BUMPERS. Precisely in the percentages that they gave. If Arkansas contributes one percent of the total of the trust fund, we get one percent back, after minimal administrative costs are subtracted. We allow HHS to deduct their expenses for administering the program. So, the net cost to the Federal Government is zip.

Senator **BAUCUS**. The net costs were not much, anyway, compared to similar programs. Senator, thank you very much for your testimony.

Senator **BUMPERS**. Thank you very much, Mr. Chairman. I want to publicly thank Congressman Doug Walgren from the House who has introduced the identical bill there, and he is here to testify.

Incidentally, Dr. Tom Starzl from the University of Pittsburgh has one of the best, if not the best, liver transplant programs in the country. Dr. Starzl and I both got Honorary Doctorates out at Northwestern two or three years ago, and he has been mad ever since because they asked me to deliver the luncheon speech. So, today is his chance to get even; and I am very glad that he is here. (Laughter)

They didn't ask you to do any transplants, did they? (Laughter)

Our next witness is Doug Walgren, Congressman from Pennsylvania. We are very happy to have you here.

STATEMENT OF HON. DOUG WALGREN, A U.S. REPRESENTATIVE FROM PENNSYLVANIA

Congressman **WALGREN**. Thank you very much, Mr. Chairman. It is an honor to appear before you today to testify on what is a very critical problem for our health care system and for our spirit, I think, as a nation.

I represent Pittsburgh, Pennsylvania in the House of Representatives, or parts of the surrounding area, and have come to know the transplant program at Children's Hospital, which has in large part been headed up by Dr. Tom Starzl, who will be a witness following me today.

I think the Pittsburgh area has been stunningly aware of the tragedies that face families who are unable to raise the money to pay for transplants and the trauma that they are put through. I have introduced H.R. 5330, which is a companion bill to the bill introduced on the initiative of Senator Bumpers in Senate.

As Senator Bumpers said, it would create a check-off on the Federal tax return for taxpayers to be able to direct any portion of their tax refund or add a cash contribution to the national organ transplant trust fund.

Now, we ought to emphasize—and I think it is somewhat sad that we have to emphasize—that we are not here asking for any Government money. We are not here asking the taxpayers to contribute one dime of taxes to try to accomplish this purpose.

We are simply trying to create a broad-spread opportunity for people to recognize this need and make their own individual charitable contribution. The Department of the Treasury would simply be a collection system that would return to each State the funds collected by citizens, and each State would then establish a program to help needy people in that State pay for organ transplants.

The basic problem, as you know, Mr. Chairman, is that this bill addresses the fact that current insurance is essentially, for all practical purposes, nonexistent in many, many, many cases. People today literally have to beg for the money to pay for transplants.

Many of them come to us and, as individuals, there is hardly much we can do. Some have gone to the President; and from time to time, some individual case will catch the eye of The White House and focus attention on it. But many are out there looking for help.

Patients struggling for their lives should not have to reach for bake sales, cry in press conferences, all to try to raise money to save a loved one. Their survival should not depend on political connections; it shouldn't depend on where they live. It shouldn't depend on whether they might happen to find some individual angel who is in a position to come in and provide this kind of care.

A country that has the wealth that we do should be able to find ways to pay for necessary medical care without putting people to begging in the streets. A compassionate country as abundant as ours is in resources should not turn people away at any stage of a hospital door to die because they cannot pay for medical help.

We know that organ transplants are terribly expensive, and they are essentially—as you said, Mr. Chairman—prohibitively out of reach of most people. The average liver transplant costs range around $200,000; heart transplants approach $100,000. Kidney transplants cost between $30,000 and $40,000.

And although there is some coverage of private insurance, in many cases, as I say, it is simply not there. Even if insurance is to cover 80 percent of these costs, it remains out of reach and prohibitively expensive for many individuals in our economy to pay the remaining deductible.

Medicaid coverage for the poor varies from State to State, but first you have to be poor; and many families do not initially qualify for Medicaid. We have seen the outright refusal of States to provide State funds because they are so limited to pay for such an important benefit, largely because it is there only for one individual.

Virginia refused to pay Children's Hospital in Pittsburgh recently for the costs of a liver transplant. The child's family had to sue in Federal court in Virginia. They were sustained, and Virginia was ordered to pay; but they were sustained under a law that can then be conformed by Virginia to eliminate their obligation to support that kind of life-giving social support.

The State of Oregon has essentially gotten out of the business of paying for any transplants, simply because they felt they were able to do more good with the money, reaching more people, in women and infant children care. That is certainly true, but it also means that there are children and adults in Oregon who will have no access to this kind of support to pay for transplants and essentially will be condemned to die because we have not put the money in place.

We have great costs with immunosuppressive drugs that come after a transplant; and although Medicare has taken some steps in strengthening that program, we essentially leave these costs—$5,000 a year after one or two years—to the individual involved.

The result of this patchwork of health insurance coverage is that, for most American people—certainly the broad swathe of middle income Americans—organ transplants are something that is not within their reach.

All of these costs then leave the institutions which perform transplant without a payment support system, with the choice of either turning the patient away at the outset or of incurring very large substantial losses that undercut the ability of those medical facilities to continue.

The best and long-term situation, of course, to solve this problem is to include transplants in some broader social system; but we are not there yet because the budget won't allow us. The least we can do under those circumstances is try to encourage individuals to make some contribution to what is such a dramatic social need.

Organ transplants represent the frontier of medicine, and that may be the most important reason why it should be supported. We don't know where the knowledge that will come out of working on the level that organ transplants bring science—we don't know where that will lead. We don't know what good it will enable us to do. It may very well be that the knowledge developed in that area down the road will eliminate many costs in our system.

So, as a Nation we know, I think, that we withhold ourselves from science really at our peril. And I think, too, that we ought to be thinking about what we want to be as a country.

In the 1800s and the 1900s, largely through the Statue of Liberty and the opportunity that lay behind it, we were seen by the world as a land of opportunity and a land of political freedom and personal freedom. The question really is what we want to be seen as by the world and how we want to see ourselves in the twenty-first century.

We have the opportunity, if we put the science in place with the right support, to be seen as the nation that can be the giver of life itself. That may be the most important thing for America's future in the long run in so many ways.

So, Mr. Chairman, I hope that you and others on this side of the Capitol, and I know many on my side, will be trying to put in place this little step that only makes sense and certainly doesn't take anything away from the taxpayers or damage the budget or open ourselves up in any way to some unended, large-scale loss of the tax revenue that we all know is spoken for in so many ways in these years.

Thank you very much for the opportunity to come and talk with you, Mr. Chairman. If there is anything further I can add, you know I would be happy to.

[The prepared statement of Congressman Walgren appears in the appendix.]

Senator BAUCUS. Thank you very much, Congressman.

The question that comes to everyone's mind is where to draw the line. That is: Under what other circumstances or what other provisions should the tax return also have a check-off provision?

We already have a check-off provision for presidential campaigns. Based upon the last several weeks in this presidential campaign, not many people would say it is life threatening, that is the presidential campaign. (Laughter)

The point is that we do have a check-off system for presidential campaigns; and if we were to have one for organ transplants, the question that must be asked and I think has to be answered is: Where does one draw the line? What other needy causes or purposes do we have where we should provide similar treatment? What about cancer? What about brain surgery?

We could come up with a long list of potential candidates for a check-off system. I am wondering why a check-off should apply for organ transplants but not for others; and if for others, where does one draw the line?

Congressman WALGREN. Mr. Chairman, I see us as taking some stopgap steps here that will provide some essential sustenance to the support of the initial development of transplant capabilities and the science of transplants. We presently invest taxpayers' money in cancer and substantial amounts of taxpayers' monies in other critical health problems.

We should ultimately be moving transplants into that area of our recognized social support as well, but we can't do that right now. We have transplant teams that could be really advancing our knowledge in critical ways if they had some sustenance, and this is the way to do it.

I saw in the paper the other day where Japan has in all their post offices essentially a reminder that people should set aside some of their money to buy high-definition television so that the Japanese will be first and foremost in the production and marketing of the new high-definition television.

I would much rather my country have a set-aside for life-giving medical care than for some consumer technology. Wherever we draw the line, it is some place on the other side of organ transplants.

Senator BAUCUS. Do you think ultimately it would be better to have a health care system that provided sufficient insurance to cover organ transplants, instead of having a check-off system with a separate trust fund only for organ transplants?

Congressman WALGREN. Clearly, this science is going to go to the point where the costs are going to be blended in with the other traditional systems we have of giving to each other to pay for the medical care that we may be fortunate enough individually not to need, or at least not just now.

Essentially, in our medical systems, there are ways that we contribute ourselves, both for our own care and for that of others. This is nothing different, and ultimately it should go in the same direction and be considered the kind of thing that we contribute to accomplish as a society.

Senator BAUCUS. Thank you very much, Congressman. I see that Senator Chafee is with us, and he will be part of this hearing. Thank you very much for your testimony.

Congressman WALGREN. Thank you very much, Mr. Chairman.

Senator BAUCUS. Our next witness is Mrs. Sherry Clifton of Silver Spring, Maryland.

Mrs. Clifton, we welcome you to this hearing and very much look forward to your testimony.

STATEMENT OF SHERRY CLIFTON, SILVER SPRING, MD

Mrs. CLIFTON. Thank you. I feel honored to be here this morning because this is something that is very, very close to me. I went through it. I went through the begging to save my husband's life. It is an ordeal that I would not wish on anyone.

In 1984, my husband was admitted to Southern Maryland Hospital; having congenital heart disease, we were accustomed to that heart failure, and he had had one pacemaker implant in 1977. They tried a second implant in 1984, but they found that nothing was going to work for him. He was dying, and there was nothing they could do, nothing more they could do.

His cardiologist said that his only hope was a heart transplant, and I was just glad that we had hope. So, I wasn't really concerned about it. I mean, he had Maryland medical assistance; this was something that was needed. It was a medical problem, and I just thought that everything would be all right.

But then, I was told that Maryland medical assistance considered the heart transplants as not quite regular—it was still in the experimental stages. So, they would not pay for it.

After the doctor called around to the transplant centers—his cardiologist called them—to see if they would accept him, the Medical College of Virginia was the lowest. They would accept him with a $30,000 deposit. We were both disabled. My husband's only insurance is with Maryland medical assistance. He was on SSI, and I was on SSA; and I had Medicare and Medicaid, and he only had Medicaid.

We had no property. We had no way of raising any money. We had no assets at all. So, here we were faced with $30,000, and MCV would not back down. They were adamant; they said they would not admit him.

So, then I thought about the health organizations because I am an American, you know; and I know that we take care of our own. I started with the Heart Association, and they told me they were set up to educate people to prevent heart disease, not to help people who were dying of heart disease.

So, I went on down the line—the United Way, the United Givers Fund, the United Black Fund, the Red Cross—all of the so-called help organizations; and each one turned me down. I then turned to the media. I got newspaper coverage, TV coverage, radio coverage, and starting asking for donations to try to raise the $30,000.

And as I heard in testimony earlier, it is much easier to raise money for a child. People are more receptive to trying to save the life of a child, but my husband was 49 years old. And I imagine people were saying that his life was almost gone, anyway. The cutoff for heart transplants at that time was 50, and he was nearing his 50th birthday.

The money started coming in so slow; we did set up a heart fund, but the money was coming in slow. We were nowhere near the $30,000, and the doctor was giving him 2 weeks to live. I then called The White House. I did not know at the time that they even had a transplant liaison, but I just asked for one; and they said they had one.

So, I spoke to a gentleman, and he said he would see what he could do. Later on, I called back and said the situation is critical. My husband is dying; something has to be done. It is my understanding that The White House then contacted Governor Hughes, who was then the Governor of Maryland; and he contacted the Governor of Virginia to guarantee the State of Virginia payment if they would admit my husband.

He was admitted, and he was transplanted. The situation there—and I think the saddest thing—was that I had to go through this to get help. We were born here; our forefathers were born here. And when we were both able—we are disabled—but when we were both working, we paid our taxes, and we just kind of felt that the help would be there if we really needed it.

I could not see an American dying and saying that no funds were available to save his life.

I then referred to Ling-Ling and Tsing-Tsing on the last TV interview before they shipped him out. I spoke to the American people, saying we have two pandas in the zoo; and they have received the best medical care that money could provide. My husband is a human being; and everywhere I call, they are saying there are no funds available to save his life.

His life was saved. His transplant was 4 years old on September 12th; but I pray that something will be done that no other man or woman would have to go through what I went through to try to save his life, to try to raise that money, to try to get on TV and open up all of our life. I had to tell everything from beginning to end. If we had a dollar in North Carolina, that had to be revealed.

We had no privacy; we had nothing. And I had to do this in order to get him the medical help that he needed. I sincerely hope that my testimony and the other testimonies will rectify that in the future.

[The prepared statement of Mrs. Clifton appears in the appendix.]

Senator BAUCUS. Thank you, Mrs. Clifton.

What is the total cost so far?

Mrs. CLIFTON. The transplant itself was over $200,000. He was in Southern Maryland Hospital from July 2 until August 23; that cost was $36,000. The medical assistance only paid for the first 20 days. We had to pay Southern Maryland Hospital $14,970.30; that was a personal bill. Maryland medical assistance did not cover those other days.

From August 23 until November 11, he was in MCV; and that bill was over $200,000; but it would not have been that much had he been able to get in the hospital earlier because, by the time he got there—while I was trying to raise the money—his condition was so deteriorated that they had to build him back up. As a matter of fact, they weren't even considering the transplant.

Senator BAUCUS. I am a little confused. The total cost was how much? What does all that total up to?

Mrs. CLIFTON. Up to the day he was discharged, it would have been $236,000.

Senator BAUCUS. Now, what about additional medical costs?

Mrs. CLIFTON. All right. He has cyclosporin, prednazone and imuran, which are the antisuppressants which he will be on for the rest of his life.

Senator BAUCUS. And what do they cost annually?

Mrs. CLIFTON. Now that his dose is lower, I would say approximately $150.00 a month for his total medication.

Senator BAUCUS. All right. It is clear that your husband should have had a transplant much earlier. It is obvious in America, at least to me, that a heart transplant should not depend upon a person's wealth. It should not depend upon a person's financial condition.

I think that this legislation before us is a very good step to try to remedy the problem that occurs today in America, that is a medically necessary procedure like a heart transplant is available to some Americans but not others; that is obviously wrong.

The question then is: What is the best way to solve the problem. Thank you very much.

Senator Chafee may have some questions.

Senator CHAFEE. Thank you, Mr. Chairman. Mrs. Clifton, I just wanted to say that I came here not knowing much about this, and indeed, I was wondering what it was all about. You have given very, very eloquent testimony here today and have certainly raised my concern and interest in the whole matter.

You have portrayed it so vividly as it pertained to you and what you had to go through, and I think your statements regarding your being an American and having been born here, and your folks were born here before you; and here, you run into these terrible problems; and your conclusion that you don't want anybody else to have to go through the problems you went through.

By the way, did you raise the money? How did you ever do it?

Mrs. CLIFTON. We never raised the $30,000; but what was raised was enough for us to pay the $14,900 to Southern Maryland. But we did not raise the $30,000. The money was just coming in so slowly; as I said, it is more appealing for a child. But he was 49 years old, and we just weren't getting the donations.

Senator BAUCUS. I wanted to ask about the $200,000 cost.

Mrs. CLIFTON. As I said, Governor Hughes guaranteed payment.

Senator BAUCUS. I understand.

Mrs. CLIFTON. Now, it was my understanding that the Federal Government was supposed to go 50-50 with the State of Maryland. I didn't get into that, and no one has ever told me whether that was done or whether the Maryland Medicaid just paid what they pay. I think they pay 80 percent of it; but we didn't get the bills, so I don't know how it was done. But I do know it was paid for.

Senator BAUCUS. Thank you.

Senator CHAFEE. Thank you very much.

Senator BAUCUS. Thank you, Mrs. Clifton. We appreciate your testimony. Our next witness is Dr. Thomas Starzl, Professor of Surgery, School of Medicine at the University of Pittsburgh in Pennsylvania.

We are very honored to have you with us this morning. We look forward to hearing your expert testimony. Why don't you go ahead, and proceed in any manner that you wish?

STATEMENT OF THOMAS E. STARZL, M.D., PH.D., PROFESSOR OF SURGERY, SCHOOL OF MEDICINE, UNIVERSITY OF PITTSBURGH, PITTSBURGH, PA

Dr. STARZL. Thank you, Senator Baucus and Senator Chafee. I did want to say how honored I was to be here and to testify on behalf of a bill which is supported by two of the legislators whom I admire the most in the world, our own Congressman, Mr. Walgren, and, of course, Senator Bumpers, who as you have just heard, I have known for some time.

I have, as Senator Bumpers has done, provided some pro forma material for the record which really consists of three things: first, a history of transplantation; second, a history of the funding of transplantation; and third, a suggestion of the need for some kind of rectifying legislation. And I am not going to go into that; that would be too boring.

I wanted to comment really on Mrs. Clifton's testimony. First of all, to be confronted with an age limitation as she has just described, of 50 years, or as Senator Bumpers mentioned, doesn't seem to me to be right. I suppose there has to be some kind of limitation for candidacy; but up to this point, the recipients of livers or hearts or kidneys who are beyond the age of 50 have not had a degraded survival—a poorer survival—than those who are younger.

So, as a criterion for selection or admission to some kind of a support structure, I think it is illogical and probably even unethical to have an age limitation. For the record, our oldest liver recipient—and a very controversial one—was 76 years old. She is now 79 years old and really lives a completely normal life, having been liberated from the hospital.

The second point that I wanted to comment upon about Mrs. Clifton's testimony, is the cost of caring for people without regard for transplantation. You heard from her an exposition of certain figures which were the costs of caring for her husband at general hospitals while waiting for transplantation. And these figures, which she added up to more than $30,000, become astronomical.

So, at that point, as these hospitalizations and chronic disease increase, what one is looking at is really a question not so much of whether or not transplantation should be in the picture, but whether or not someone with heart disease should be treated at all.

Once the decision is made for treatment, it seems to me that the secondary question—the derivative question—should be: What is the best way? Rather than having a "yes/no" situation, as far as transplantation is concerned.

I think I can answer your question about who ate those $200,000 losses. Those losses were eaten by the Medical College of Virginia, who secretly almost in order to avoid playing any role, particularly as a villain, in this moral play, decided to go forward and to carry out therapy. But they did it secretly because they couldn't afford to become an indigence center for the world.

So, I think Mrs. Clifton owes a debt of gratitude actually to MCV that she probably doesn't fully appreciate because they, without question, almost certainly were never paid for their services.

Now, as far as the formal presentation is concerned, the history of transplantation is breathtakingly short. The first batch of successfully treated kidney recipients came pouring out of clinics, somewhat to everybody's amazement, a few months after President John Kennedy was inaugurated.

Three weeks before the inauguration, there was an article in the New England Journal that pronounced the possibility of transplantation to be nonexistent; and by the time President Kennedy was assassinated, this had already become a service for renal transplantation. So, the history of this is so short that, in many ways, assimilation of the technology into our fiscal systems or into our insurance systems has not kept up with the pace of development.

As to the steps in the development, one only should mention that the key issue has been better drugs to prevent rejection; and the most important recent step was the introduction of a drug called Cyclosporin, which suddenly made practical the transplantation of livers and hearts, which up until that point had been unreliable and unpredictable.

The history of funding may be more of interest to this group. This was a specialty in which the drive and the initiative came from the Government; the Government through NIH funding fed this dream—this impossible dream—of transplantation and allowed or promoted a technology to develop which gave the United States the leadership, a leadership which goes on today.

Then, to answer a question that you raised as to how other countries deal with this, they actually deal with the spread of transplant technology through their government agencies. So, the idea of having a disenfranchised constituency in Sweden, for example, or England or France would be almost unthinkable.

We train the people that go from the United States to these different countries, and they are sent not only to well developed countries but to third world countries. So, mechanisms have been found abroad to sweep in the American technology.

Japan was mentioned, and Japan is going to be the latest of the countries that will profit by the advances made in the United States; and in the long run, if we are not careful and don't come up with some mechanisms to care for our own people, we will be left behind in the vanguard of those countries which now seize the lead from us.

Senator CHAFEE. Mr. Chairman, I wonder if I could interrupt for one moment? Unfortunately, I have a prior commitment that I absolutely have to meet. If I could just interrupt Dr. Starzl for a couple of questions?

Dr. STARZL. Yes, of course.

Senator CHAFEE. I have a couple of questions. Could we say that these transplants save money in the end in many instances because it isn't always a question of life or death on the part of the person—that is the recipient—but frequently, it is a case of the person being chronically ill, requiring tremendous hospital care, absent any transplant, and the transplant itself—expensive though it might be—releases that person from this constant medical attention, which in many instances is being paid for by the public, anyway? Is that a fair statement?

Dr. STARZL. You said it more perfectly than I did or could. I think it is a fair statement, and that whole cycle of development to the point you have just described has already occurred unequivocally with renal transplantation in which it is cheaper and it is better and it is more socially useful to be treated with transplantation than any alternative form of therapy.

We are heading in that direction if, in fact, we haven't already reached it, as witness the Clifton case, with heart and with liver transplantation as well.

[The prepared statement of Dr. Starzl appears in the appendix.]

Senator CHAFEE. These statistics that you have on chart one are really dazzling, particularly heart.

Senator BAUCUS. I wonder, Senator, if you could hold up just a second. We are going to have a vote at 11 a.m., and we have one more witness. I wonder if Dr. Klintmalm could come up, please, so that we will have a panel here? Otherwise, I am afraid that we are going to get cut short here on time, and that is not going to be fair to the witnesses.

I wonder, Senator, if you could be brief in your questions because we are going to be cut pretty close here.

Senator CHAFEE. Sure. Briefly, do some of these patients return to a normal life to the extent that they can work?

Dr. STARZL. Ninety percent of the liver and heart recipients return to the workplace.

Senator CHAFEE. Do you agree with that, Dr. Klintmalm?

Dr. Klintmalm. Yes.

Senator CHAFEE. And the other question is: Absent this, many of them would have been chronically requiring medical services of a high-cost nature?

Dr. STARZL. That is right.

Senator CHAFEE. Do you agree with that?

Dr. Klintmalm. Correct.

Senator CHAFEE. All right. Thank you.

Senator BAUCUS. Dr. Klintmalm, why don't you give your statement right now, too; and then, I will have questions for both of you.

STATEMENT OF GORAN KLINTMALM, M.D., PH.D., DIRECTOR, TRANSPLANTATION SERVICES, BAYLOR UNIVERSITY MEDICAL CENTER, DALLAS, TX

Dr. KLINTMALM. I have submitted my statement, and I think I can save time if I just make some brief comments. I am very pleased to be able to be here to be a witness for your committee, Mr. Chairman.

The central issue here is how we shall be able to deliver health care for all those that need it, and no one—I don't think any nation—can afford to give all possible health care to all its needy individuals.

We have a problem here in the United States in that the funding for transplantation is different from that in my native country, Sweden, where there is a national health service and everything is paid for automatically. No one asks questions.

But I think we can very easily show, as stated by Dr. Starzl, that you don't die at home from liver disease, for example, in this country. You die in the intensive care unit, and that is a very expensive mode of dying.

Dr. Evans actually showed in 1986 that each trip to the intensive care unit to die with these complications costs about $18,000—each trip. You usually have several of those behind you before you die.

So, in essence, for the same amount of money, you can actually either have a patient die or you can have the patient return back as a useful citizen—useful to himself, to his family, to society.

Also, I think we should keep some perspective of what is the cost. I think that the cost we have heard about is something that is coming down dramatically. At Baylor in Dallas, the average cost for liver transplant is $100,000; and actually, two-thirds of the livers are done for much less money than that.

I think I would like to support this bill here in that it provides a new innovative form of funding for transplants that we need, especially with today's budget restrictions. This is a new approach. The American people have always been willing to help each other out, and I think this is a new way to do so.

Also, finally, this bill does not introduce new bureaucracy or other problems in the handling of these funds, and this is also one of the reasons why I support the bill. Thank you.

If you have any questions, I will be glad to answer them.

[The prepared statement of Dr. Klintmalm appears in the appendix.]

Senator BAUCUS. Thank you, Doctor.

Senator BAUCUS. In Sweden, are transplants covered by universal health insurance?

Dr. KLINTMALM. Yes.

Senator BAUCUS. So, if someone needs a heart transplant, whether he is wealthy or not wealthy, the health insurance system in Sweden will cover, if not all transplants, at least the medically necessary transplants?

Dr. KLINTMALM. That is correct. All transplants that are medically necessary are being covered, and no questions are asked.

Senator BAUCUS. I would like to ask both of you the question I asked Congressman Walgren; that is: Where does one draw the line? I mean, there are other maladies that beset people in life, whether it is cancer or whatever. I am wondering, as physicians, whether you think that this check-off system should apply only to organ transplants, or are there other kinds of medical procedures which also should be covered under a similar check-off system, if not the same one?

Dr. STARZL. As Dr. Klintmalm already mentioned, the transplant field is not really handled in quite the same way as other conventional forms of treatment. And one of the reasons for that, if I could—I was going to trace the history of funding—is that there has been an absence of signals from the Government about the genuine service nature of transplantation. And I believe that the history of funding would reveal exactly how that has occurred.

That is, in 1973 the end-stage renal disease programs were established in the United States. They became enormously expensive, primarily because they were enormously successful, but also because dialysis—which was the alternative form of therapy—was included in that bill.

Now, when legislators and bureaucrats and executives began looking at the unexpected successes and advances with the extra renal organs, namely the liver and the heart mostly, in the early 1980s, it seemed as if an administrative panic set in. And in order to shield themselves from a further avalanche of expenses, the Government itself in what I think was a bipartisan approach to the matter insisted on calling these services "experimental," just as was described a moment ago by Mrs. Clifton.

When they were pronounced experimental, this provided a refuge for many insurance carriers to say: Look, the Government says or the Medicare program says that liver transplantations are experimental for all except somebody below the age of not 50, but below the age of 18.

So, there were cross signals being given, I think; and part of the spirit of this bill, which avoids this avalanche of expenses, is that it gives a very powerful signal that, as far as the Government is concerned, that game is finished, that we do recognize that there is a moral imperative to treat all of our patients and not to exclude that 60 million people who do not have means of payment from this technology.

Now, transplantation is a very special issue in the history of medicine now because it represents a right-angle turn from anything that ever happened before; and thus, it has wrought a change in philosophy by which organ-specific diseases can be approached.

Senator BAUCUS. Are you saying then that the check-off system should apply only to transplants?

Dr. STARZL. I think that you could consider every case on its own merit; but if you will grant me that, then I am merely building for you a powerful case on its own merit to have a check-off system for transplantation, at least now, so that one can build with that beginning a more stable platform. What that platform might be, I am not certain—10 years down the line—for this revolutionary technology.

I don't want to build a case against anything. I am merely building a case for transplantation because, as I was saying, it changes the whole approach by which medicine is practiced.

Look at Mrs. Clifton as an example, in which Mr. Clifton, the objective, was not to give more drugs, not to sit around in an ICU, not to give diuretics, but to replace the engine. And that is an electrifying thought which occurs to specialists with hearts, with livers, and with kidneys; and for that matter now, with lungs and pancreases.

So, it is a whole new dimension to the practice of medicine, and it needs a powerful and supportive signal from our own Government.

Senator BAUCUS. Could you also go into a little more detail on the degree to which you think that the costs would decline with greater accessibility?

Dr. STARZL. Yes, sir. When I started with kidney transplantation in a cohort of patients, which were really the first ones other than twins to survive after transplantation, the patients were treated in clinical research centers. The cost per renal transplantation in 1962 was $100,000. The cost for renal transplantation in 1988—26 years later—is between $20,000 and $25,000.

Senator BAUCUS. And that is with inflation?

Dr. STARZL. So, the real cost has gone down, something on the order, I would think, of about 1/40th of what it was in the developmental days. Dr. Klintmalm has told you a similar story in the evolution of liver transplantation. The figures being given for hearts are probably also higher than they are in this day and age.

So, there is a movement toward reduction of expenses; and as Senator Chafee was so interested in, there is a replacement saving.

Otherwise, one is confronted with the necessity of—in a Mr. Clifton—to reach the decision that, at a certain severity of illness, heart disease will no longer be treated.

Senator BAUCUS. Do some other countries have some higher developed transplant technology compared to the United States?

Dr. STARZL. I would say that other countries have managed transplant technology. We still have a lead in transplantation. I doubt if anyone would really argue with that. But I would say that they have managed the practical fruits of transplantation in a more equitable way.

Sweden, where Dr. Klintmalm has worked, is a perfect example. Most of the transplant surgeons in Sweden were trained by me and then went back to Sweden, and the arrival of some of the transplant practices—for example, liver transplantation—were rather recent, for example 1984. But having arrived, a system was immediately put in place in Sweden in which no person because of lack of money is deprived of treatment.

So, I would say that, at an administrative level, they have switched gears far more smoothly than we have in the United States.

Senator BAUCUS. Are there any transplants that are theoretical today but perhaps are actual tomorrow?

Dr. STARZL. Yes, there are.

Senator BAUCUS. What are some of those?

Dr. STARZL. The most practical thing, and actually this is already on line in a very limited way, is the use of multiple transplants; that is, combinations of organs, such as the G.I.tract plus the liver and pancreas, for example.

Senator BAUCUS. G.I. means gastrointestinal?

Dr. STARZL. Yes. You can transplant intestines plus other things. That has already been done with a little girl over in Pittsburgh last year, and it is being done with smaller combinations of organ clusters daily.

We did one over the weekend in which the liver, the pancreas, and part of the small bowel was transplanted as a unit in a patient who had an otherwise-untreatable cancer of the liver and pancreas. Now, this is a different issue. It is not just any more a "nuts and bolts" treatment of the person with ordinary organ failure, that kind of disease; but what we are talking about now is the use of the technology itself to push back frontiers and to open up whole new areas of potential therapeutics.

But I hate to see that happen with a disenfranchised segment of the population which tends to be the minorities, tends to be poor. I think it creates an integrity problem for everything we do when that occurs.

Senator BAUCUS. Let me ask one final question, and that is on availability of organs. To what degree is availability a limiting factor? If this bill is passed, the financial end will not be a problem, but availability may be. I am wondering the degree to which transfers are limited.

Dr. STARZL. It is a limitation. Yes, sir. It is a limitation; but let me say that I don't know if that limitation is really as extreme as is sometimes said. I do think there is a limitation, but at the moment, what happens is that a third of the population approximately——

If there were 2,000 of anything, 2,000 hearts for example, the way it is at the present time is that those 2,000 hearts will go to 2,000 recipients, maybe minus a few, who have the money, who have the means, who have the political connections to have this happen. And that is what I think strikes the moral cord, and that is an issue toward which these bills in the House and Senate are directed.

So, I think what we are seeing here this morning and what we are appealing about is not a money matter so much as a moral issue; and this is a step in the direction of resolving a moral issue. I hope, for that reason, that the bill is favorably considered.

Senator BAUCUS. I want to thank you and all the witnesses. You have collectively made a very compelling case. It is not only the personal tragedy of disenfranchisement. When a patient is unable to receive an organ because he or she is unable to pay for it, that in itself is sufficient reason for finding some solution. But you have also very well documented the replacement costs to society, that is, the greater cost in trying to keep a person alive than would be the case if that person were to receive a transplant. Replacing the engine, as you say, is a very good point to differentiate organ transplants from other forms of medical procedures.

Dr. KLINTMALM. Mr. Chairman, may I just add on to that statement? You asked about the donors. I don't think that that is the limiting factor, but it is one of them.

There are organs being buried every day in the United States because we cannot place them in an appropriate recipient—an appropriate recipient in that blood group or that age or that weight range in the United States. It is who can pay.

This happens every day that we have to leave organs unused because there are no recipients who can take them.

Senator BAUCUS. I understand that, but that is a separate point. What we are addressing today in this bill is availability because of cost, not because of supply.

Dr. KLINTMALM. Exactly.

Senator BAUCUS. Or because of other medical reasons.

Dr. KLINTMALM. Exactly. I just want to say that it is not the availability of the organ that is the only limitation. The ability to pay is also a limitation for the spread of transplantation.

Senator BAUCUS. Yes. Thank you all very much. The subcommittee will take this bill under consideration, and again I want to thank all the witnesses, and Senator Bumpers and Congressman Walgren for their introduction of the bills. The hearing is adjourned.

[Whereupon, at 11:12 a.m., the hearing was adjourned.]

APPENDIX

Alphabetical List and Material Submitted

DESCRIPTION OF S. 2409

(DESIGNATION OF OVERPAYMENTS AND CONTRIBUTIONS ON TAX RETURNS FOR NATIONAL ORGAN TRANSPLANT TRUST FUND)

Prepared by the Staff

of the

JOINT COMMITTEE ON TAXATION

INTRODUCTION

The Subcommittee on Taxation and Debt Management of the Senate Committee on Finance has scheduled a public hearing on September 20, 1988, on S. 2409 (introduced by Senator Bumpers). The bill would provide that taxpayers could designate on their tax returns all or a portion of their tax refunds (or could make contributions with their returns) to a new Federal trust fund that would be used to defray the costs of necessary organ transplants.

The first part of the document[1] is a summary of the bill. The second part provides a description of present law and of the provisions of S. 2409.[2]

I. SUMMARY OF S. 2409

Under present law, individual taxpayers may elect on their income tax return to allocate $1 ($2 on a joint return) of their tax liability to a fund established to provide financing to Presidential election campaigns. Federal tax law does not permit taxpayers to make contributions for charitable or other purposes through their Federal income tax returns.

The bill would provide that taxpayers could designate on their tax returns all or a portion of their tax refunds (or could make contributions with their returns) to a new Federal trust fund that would defray the cost of necessary organ transplants. The designation of contributions to the trust fund would be effective for returns filed for taxable years ending after the date of enactment.

II. DESCRIPTION OF S. 2409

Designation of Overpayments and Contributions on Tax Returns for National Organ Transplant Trust Fund

Present Law

Under present law, individual taxpayers may elect to allocate $1 ($2 on a joint return) of their tax liability to the Presidential Election Campaign Fund, a fund established to provide financing to the campaigns of presidential and vice-presidential candidates (Code sec. 6096). The election is made on the first page of the taxpayer's return. An election to make an allocation to the fund neither increases nor decreases the taxpayer's liability, but merely determines whether the allocated amount will be used by the Federal Government for campaign funding.

No other provisions of Federal tax law permit taxpayers to designate for what purpose the amount of tax owed is to be used by the Government. Present law does not permit taxpayers to make contributions for charitable or other purposes through their Federal income tax return.

The Commissioner of Internal Revenue, in the instructions to Form 1040, has encouraged taxpayers to include with their tax return voluntary contributions to reduce the public debt. Taxpayers wishing to do so must enclose a separate check payable to the Bureau of Public Debt.

Explanation of the Bill

Designation of amounts for Organ Transplant Trust Fund

Under the bill, taxpayers[3] entitled to an income tax refund could irrevocably designate all or any portion of the refund as a contribution to the National Organ Transplant Trust Fund, a trust fund to be established by the bill within the United States Treasury. The bill would require that the designation appear on the first page of the return.

Taxpayers not entitled to a refund, or who wished to make a contribution to the Fund in excess of their refund, could include an additional amount with their return and designate this as a contribution to the Fund. The designation would not increase or decrease the tax liability of a taxpayer for the year covered by the return.

Disposition of amounts in Trust Fund

Under the bill, each State would establish a program to receive payments from the Fund and to provide financial assistance to individuals with a medical condition for which an organ transplant procedure is medically necessary, who lack the financial resources to pay for such procedures. A State also could use funds from the Trust to pay for costs incurred by the State's chief health officer to publicize the availability of the Trust Fund and to solicit contributions to the Fund, except that such payments could not exceed five percent of the total payments received by the State from the Trust Fund for the Year.

Specific rules and procedures relating to State residency and the medical and financial eligibility of individuals for benefits under a State's program, which medical expenses would be eligible for payments from the program, the maximum amounts payable, the terms and conditions under which payment will be made to eligible individuals, and other relevant determinations, would be prescribed by regulations issued by the chief health officer of each State.

Amounts in the National Organ Transplant Trust Fund would be disbursed by the Secretary of the Treasury to those States which had been certified by the Secretary of Health and Human Services as carrying out their programs in accordance with the bill and fully accounting for the money received from the Fund for the previous year. Expenses incurred by the Treasury Department in administering the program also would be payable out of the Fund.

Effective Date

The designation of contributions to the Trust Fund would be effective for returns filed for taxable years ending after the date of enactment. The Trust Fund would be established on the date of enactment.

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[1] This document may be cited as follows: Joint Committee on Taxation, Description of S. 2409 (Designation of Overpayments and Contributions on Tax Returns for National Organ Transplant Trust Fund) (JCX-29-88), September 16, 1988.

[2] A description of S. 2409 also appears in JCS-12-88, July 11, 1988, which was prepared for the Subcommittee hearing on various tax bills on July 12, 1988. S. 2409 was removed from the July 12 hearing list after the hearing pamphlet went to GPO.

[3] It is intended that this provision apply only to individual taxpayers.

STATEMENT OF SENATOR DALE BUMPERS
ON
S. 2409, THE COOPERATIVE ORGAN TRANSPLANT CONTRIBUTIONS ACT

MR. CHAIRMAN, I WANT TO THANK YOU FOR SCHEDULING THIS HEARING AND PROVIDING THE FORUM FOR DISCUSSION OF THE IMPORTANT ISSUE OF FINANCING ORGAN TRANSPLANTS FOR THOSE WHO NEED BUT CAN'T AFFORD THEM. S. 2409 IS A BILL WHICH WOULD ESTABLISH A WAY FOR THE AMERICAN PEOPLE TO HELP THOSE WHO NEED TRANSPLANT SURGERY. THIS BILL IS COSPONSORED BY A NUMBER OF MY DISTINGUISHED COLLEAGUES, INCLUDING SENATORS INOUYE, SANFORD, PROXMIRE, STAFFORD, CONRAD, CHILES, HEFLIN, FORD, HATCH, AND THURMOND.

ORGAN TRANSPLANT PROCEDURES ARE SIMPLY MIRACULOUS, AND WE CAN BE PROUD AS A NATION THAT OUR PHYSICIANS AND SCIENTISTS HAVE BEEN PIONEERS IN DEVELOPING LIFE-SAVING TRANSPLANT PROCEDURES FOR LIVERS, HEARTS, AND KIDNEYS AS WELL AS OTHER ORGANS AND TISSUES. THESE OPERATIONS ARE DAILY SAVING THE LIVES OF DOZENS WHO WOULD OTHERWISE DIE.

THERE ARE TWO BIG CONDITIONS THAT MUST BE MET BEFORE ORGAN TRANSPLANT SURGERY CAN GO FORWARD: A SUITABLE ORGAN DONOR MUST BE FOUND AND RESOURCES MUST BE AVAILABLE TO PAY FOR THE PROCEDURES. FORTUNATELY, THIS COUNTRY IS MAKING PROGRESS IN DEVELOPING A SYSTEM TO OBTAIN AND DISTRIBUTE ORGANS FOR USE IN TRANSPLANTATION SURGERY. THE CONGRESS HAS CERTAINLY HELPED BY REQUIRING HOSPITALS TO REQUEST THAT FAMILIES OF DECEASED PATIENTS DONATE THE ORGANS OF THEIR LOVED ONES. THIS LAW AND THE HARD WORK OF MANY PEOPLE IN PRIVATE AND PUBLIC ORGAN PROCUREMENT AGENCIES ARE HAVING A POSITIVE EFFECT ON THE SUPPLY OF ORGANS. NONETHELESS, ORGAN AVAILABILITY IS STILL A FORMIDABLE QUESTION WHEN AN INDIVIDUAL IS FACING TRANSPLANTATION SURGERY. TRAGICALLY, TRANSPLANT PATIENTS SOMETIMES DIE WHILE WAITING FOR A

SUITABLE ORGAN. WE MUST CONTINUE FEDERAL EFFORTS TO COORDINATE AND IMPROVE ORGAN PROCUREMENT IF THE SUPPLY OF ORGANS IS TO MEET DEMAND.

JUST AS TRAGICALLY, IN THIS BOUNTIFUL AND GENEROUS NATION, WE ALLOW TRANSPLANT CANDIDATES TO DIE BECAUSE THEY DO NOT HAVE INSURANCE COVERAGE OR PRIVATE RESOURCES ADEQUATE TO PAY FOR A TRANSPLANT PROCEDURE. ORGAN TRANSPLANTATION IS VERY EXPENSIVE. THE COSTS OF A LIVER TRANSPLANT AVERAGES $265,000; A HEART TRANSPLANT $125,000; AND A BONE MARROW TRANSPLANT $95,000. THE IMMUNOSUPPRESSIVE DRUGS THAT ARE REQUIRED FOR THE REST OF A PATIENT'S LIFE COST $6,000 TO $10,000 ANNUALLY. BUT THIS COUNTRY HAS ALWAYS VALUED THE INDIVIDUAL LIFE AND FOUND A WAY TO GET LIFE-SAVING MEDICAL CARE TO THOSE WHO NEED IT.

THERE ARE MANY PATIENTS IN THIS COUNTRY WHO NEED TRANSPLANTS BUT ARE EXPERIENCING GREAT DIFFICULTIES FINANCING THEM. THESE PATIENTS MUST PROVE THEY HAVE THE RESOURCES TO FINANCE THEIR TRANSPLANT BEFORE THEY CAN EVEN BE PUT ON AN INSTITUTION'S WAITING LIST FOR SURGERY AND FOR AVAILABLE ORGANS. MANY OF THESE PATIENTS ARE RAISING MONEY THROUGH PUBLIC APPEALS. IN ESSENCE, THEY MUST GO BEGGING FOR THE MONEY TO STAY ALIVE, OR TO KEEP THEIR CHILDREN ALIVE. THEY ARE APPEALING TO THEIR NEIGHBORS, THEIR CHURCHES, TO THE MEDIA, AND TO PUBLIC OFFICIALS FOR HELP IN RAISING THE FUNDS TO PAY FOR THESE OPERATIONS. COMMUNITIES HAVE OFTEN RESPONDED IN MULTIPLE AND CREATIVE WAYS TO RAISE MONEY -- SO THE GENEROSITY IS THERE. AND THAT IS AN IMPORTANT POINT I'LL RETURN TO.

WE HAVE TO ASK THE QUESTION, IS THIS SITUATION ACCEPTABLE? IS THIS WHAT IS BEST FOR THE PATIENT AND HIS FAMILY? I THINK

YOU'LL AGREE THE ANSWER IS NO. A PATIENT'S FAMILY SHOULD NOT HAVE TO BE OUT HUSTLING DOLLARS WHEN THEY NEED TO BE COMFORTING AND SUPPORTING THE PATIENT. FURTHERMORE, ATTEMPTS AT FUNDRAISING DON'T WORK ALL THE TIME. IT'S MUCH EASIER TO RAISE MONEY IF THE PATIENT IS A YOUNG AND PHOTOGENIC CHILD, AND MUCH HARDER IF THE PATIENT IS NOT. THERE CAN ALSO BE A DARK SIDE TO THIS FUNDRAISING BUSINESS. THERE HAVE BEEN REPORTED INSTANCES WHERE FUNDS WERE MISSPENT OR RAISED USING MISLEADING STATEMENTS. BUT, EVEN IF EVERY CENT WERE COLLECTED AND SPENT HONESTLY, I WOULD STILL OBJECT TO THIS DEMEANING SITUATION WHERE FAMILY MEMBERS HAVE TO GO OUT PLEADING FOR THE MONEY TO PAY FOR TRANSPLANT OPERATIONS.

WHY DO PATIENTS FIND THEMSELVES IN THE UNENVIABLE POSITION OF RUNNING BAKE SALES TO LIVE? THEY FIND THEMSELVES IN THAT POSITION BECAUSE THEY DO NOT ENJOY PRIVATE OR PUBLIC HEALTH INSURANCE COVERAGE FOR TRANSPLANTS.

THE FINANCING OF TRANSPLANTS IS A CRAZY QUILT OF INSURANCE COVERAGE. MEDICARE FINANCES AS MANY AS 90% OF THE KIDNEY TRANSPLANTS IN THIS COUNTRY THROUGH THE END STAGE RENAL DISEASE PROGRAM. MEDICARE ALSO COVERS HEART TRANSPLANTS AND LIVER TRANSPLANTS IN THOSE UNDER AGE 18, WHICH EFFECTIVELY MEANS MEDICARE DOES NOT COVER LIVER TRANSPLANTS. MEDICAID COVERAGE FOR TRANSPLANTATION VARIES GREATLY FROM STATE TO STATE. MOST STATES PROVIDE COVERAGE FOR SOME TRANSPLANTS, BUT SOME STATES PROVIDE NO COVERAGE AND OTHERS ARE ELIMINATING THE COVERAGE THEY PREVIOUSLY HAD. AS A MATTER OF FACT, MEDICAID COVERAGE CHANGES ALMOST DAILY. MOST OF US ARE AWARE OF OREGON'S MUCH-PUBLICIZED DECISION TO LIMIT TRANSPLANT COVERAGE IN ORDER TO FINANCE EXPANDED PRENATAL CARE EFFORTS. MY HOME STATE OF ARKANSAS IS MOVING IN THE OPPOSITE DIRECTION. THE STATE MEDICAL CARE ADVISORY COMMITTEE HAS APPROVED COVERAGE FOR HEART, LIVER, AND MOST BONE

MARROW TRANSPLANTS, AND THIS ACTION MUST NOW BE APPROVED BY THE STATE LEGISLATURE. FINALLY, PRIVATE INSURANCE COVERAGE VARIES FROM CARRIER TO CARRIER. IN SOME CASES, PRIVATE INSURANCE COVERAGE IS ADEQUATE FOR THE PROCEDURE AND ALL FOLLOW-UP CARE. IN OTHER CASES, COVERAGE IS ADEQUATE FOR THE TRANSPLANT PROCEDURE BUT NONEXISTENT FOR THE IMMUNOSUPPRESSIVE DRUGS A PATIENT NEEDS.

SO THE PATIENTS WHO NEED HELP FINANCING TRANSPLANTS ARE EITHER AMONG THE 37 MILLION WHO LACK HEALTH INSURANCE COVERAGE, THEIR HEALTH INSURANCE POLICIES HAVE INADEQUATE COVERAGE FOR TRANSPLANTS, THEY ARE UNFORTUNATE ENOUGH TO LIVE IN A STATE WITH LIMITED MEDICAID COVERAGE, OR THEY FALL THROUGH THE CRACKS IN OTHER WAYS.

ANOTHER QUESTION THAT HAS BEEN RAISED IS WHY SHOULD WE SINGLE OUT ORGAN TRANSPLANTATION FOR COVERAGE WHILE NOT PROVIDING FINANCING FOR OTHER BASIC HEALTH SERVICES. TRANSPLANTS ARE USUALLY A MATTER OF LIFE OR DEATH, AND TRANSPLANTATION FINANCING SHOULD BE TREATED AS A MATTER OF LIFE OR DEATH.

AS I SAID EARLIER, AMERICANS ARE WILLING TO BE GENEROUS TO THESE DESPERATE PEOPLE; WHAT I WOULD LIKE TO DO WITH THIS BILL IS CHANNEL THAT GENEROSITY. BRIEFLY, MY BILL WOULD SET UP A CHECKOFF ON THE 1040 PERSONAL INCOME TAX FORM, WHEREBY INDIVIDUALS COULD DONATE PART OR ALL OF THEIR TAX REFUND, OR MAKE OTHER CONTRIBUTIONS, TO A TRUST FUND FOR ORGAN TRANSPLANT ASSISTANCE. LET ME BE VERY CLEAR ON THIS POINT -- INDIVIDUALS WOULD BE DONATING THEIR OWN MONEY; THEY WON'T BE DIMINISHING FEDERAL REVENUES. THE TRUST FUND WOULD RETURN TO EACH STATE THE FUNDS CONTRIBUTED BY ITS CITIZENS. EACH STATE WOULD BE PERMITTED TO RUN ITS ASSISTANCE PROGRAM FOR TRANSPLANT PATIENTS ACCORDING TO ITS OWN REGULATIONS. STATES WOULD NOT BE REQUIRED TO APPROVE

THE TRANSPLANT PROGRAMS TO WHICH FUNDS ARE PROVIDED, BUT THEY COULD DO SO IF THEY WISHED. STATES WOULD ALSO HAVE FLEXIBILITY IN DETERMINING ELIGIBILITY FOR THESE FUNDS.

STATES COULD NOT USE THESE FUNDS AS THEIR STATE MATCH FOR MEDICAID, AND THE FUNDS ARE INTENDED TO SUPPLEMENT, NOT SUPPLANT, STATE MEDICAID EFFORTS. THE STATES WOULD HAVE TO REPORT YEARLY ON THEIR PROGRAMS AND THEIR EXPENDITURES, BUT THEY WOULD HAVE THE FLEXIBILITY TO FASHION THEIR PROGRAMS TO MEET THEIR OWN NEEDS. I FIRMLY BELIEVE THAT CITIZENS WILL WELCOME THE OPPORTUNITY TO USE THIS CHECKOFF, KNOWING THAT THEIR DONATION WILL BE HELPING PEOPLE CLOSE TO HOME.

THIS BILL HAS BEEN ENDORSED BY MANY OF THE ORGANIZATIONS THAT ARE CONCERNED WITH ORGAN TRANSPLANTATION. INCLUDED AMONG THESE ARE THE AMERICAN COUNCIL ON TRANSPLANTATION, THE AMERICAN LIVER FOUNDATION, THE CHILDREN'S TRANSPLANT ASSOCIATION, THE CHILDREN'S LIVER FOUNDATION, THE NATIONAL HEART ASSIST AND TRANSPLANT FUND, AND THE UNITED NETWORK FOR ORGAN SHARING.

MR. CHAIRMAN, I KNOW THAT SOME HAVE SERIOUS MISGIVING ABOUT THE USE OF CHECKOFFS ON OUR FEDERAL INCOME TAX FORM. I BELIEVE THESE MISGIVINGS ARE OF LITTLE SIGNIFICANCE, HOWEVER, COMPARED TO THE NEED THAT THE CHECKOFF WOULD ADDRESS. TO BE HONEST, I WOULD MUST PREFER THAT CONGRESS ESTABLISH AND FUND AN ASSISTANCE PROGRAM THROUGH THE USUAL MEANS. BUT THIS SIMPLY ISN'T GOING TO HAPPEN IN THESE TIMES OF MAMMOTH DEFICITS. THEREFORE, I AM SUGGESTING A FUNDING MECHANISM, THE CHECKOFF.

CHECKOFFS ARE WIDELY USED BY THE STATES. THERE ARE 96 DIFFERENT CHECKOFFS IN 37 STATES; LOUISIANA ALONE HAS SIX ON ITS STATE INCOME TAX FORM. ANOTHER MEASURE OF THE POPULARITY OF THE

CHECKOFFS IS THAT ALL BUT THREE STATES THAT HAVE AN INCOME TAX USE CHECKOFFS. THE IMPORTANT POINT IS THIS: THESE CHECKOFFS HAVE NOT WRECKED THE TAX-COLLECTING SYSTEM OF THE STATES AND THERE IS NO REASON TO BELIEVE THEY WOULD INFLICT ANY DAMAGE ON THE FEDERAL SYSTEM EITHER.

OF COURSE, THE FEDERAL FORM CURRENTLY DOES HAVE ONE CHECKOFF, THAT FOR THE PRESIDENTIAL ELECTION CAMPAIGN, AND IT BROUGHT IN 33 MILLION DOLLARS FOR TAX YEAR 1986. THESE RESULTS WERE ACHIEVED WITH A ONE DOLLAR PER PERSON LIMIT ON GIVING AND WITH NO ADVERTISING. WE ARE SHOOTING FOR A HIGHER AVERAGE DONATION WITH MY PROPOSED CHECKOFF, AND WE ARE HOPING THAT SOME OF THE ADVOCACY GROUPS I MENTIONED WILL PROVIDE PUBLICITY FOR THE CHECKOFF AT TAX TIME. IF WE CAN REALIZE THESE GOALS I THINK WE COULD EASILY RAISE $50-$75 MILLION FOR OUR FELLOW CITIZENS.

MR. CHAIRMAN, WE HAVE A TRULY DISTINGUISHED GROUP OF WITNESSES. I AM PLEASED TO BE JOINED BY CONGRESSMAN DOUG WALGREN, WHO HAS INTRODUCED A COMPANION MEASURE TO S. 2409 IN THE HOUSE OF REPRESENTATIVES. DR. THOMAS STARZL, FROM THE UNIVERSITY OF PITTSBURGH SCHOOL OF MEDICINE, IS THE WORLD'S MOST PROMINENT LIVER TRANSPLANT SURGEON, AND DR. GORAN KLINTMALM IS THE DIRECTOR OF BAYLOR UNIVERSITY'S DISTINGUISHED TRANSPLANTATION PROGRAM. OUR OTHER DISTINGUISHED WITNESS IS MRS. SHERRY CLIFTON, FROM SILVER SPRING, MARYLAND. SHE WENT THROUGH THE DIFFICULTIES OF RAISING FUNDS FOR HER HUSBAND'S HEART TRANSPLANT. WE ARE HAPPY THAT HER HUSBAND, HARDIE CLIFTON, IS ACCOMPANYING HER. WE COULD HAVE ASSEMBLED ANOTHER DOZEN OR SO WITNESSES, BUT WE HAVE TRIED TO RESPECT THE COMMITTEE'S TIME CONSTRAINTS.

MR. CHAIRMAN, IN CLOSING I WANT TO SAY THAT IT IS TIME WE QUIT IGNORING THE PLIGHT OF OUR FELLOW CITIZENS WHO DESPERATELY NEED HELP IN FINANCING THE COSTS OF ORGAN TRANSPLANTATION. I

WOULD GUESS THAT EVERY MEMBER OF CONGRESS HAS RECEIVED APPEALS TO HELP A CONSTITUENT WITH THE COSTS OF TRANSPLANTATION AND HAS FELT HELPLESS. WE NOW HAVE A CHANCE TO CHANGE THAT. I HOPE THAT THE FINANCE COMMITTEE WILL JOIN ME IN WORKING FOR THE RAPID PASSAGE OF S. 2409, SO THAT THE PROVEN GENEROSITY OF AMERICANS TOWARD THESE TRULY NEED PEOPLE CAN BE MORE WIDELY AND EFFECTIVELY USED.

I ASK THAT A SECTION-BY-SECTION ANALYSIS OF S. 2409 BE INCLUDED WITH MY FULL STATEMENT.

BRIEF SECTION-BY-SECTION ANALYSIS OF SENATOR BUMPERS' COOPERATIVE ORGAN TRANSPLANT CONTRIBUTIONS ACT

Sec. 1 This act may be cited as the "Cooperative Organ Transplant Contributions Act of 1988."

Sec. 2(a) Congressional findings that many organ transplant candidates are in need of assistance to pay for transplants.

2(b) Statement of the purpose of the act, which is to establish a National Organ Transplant Fund whose funds will be distributed to states in order to assist needy organ transplant candidates.

Sec. 3(a) Taxpayers may designate any portion of any tax overpayment or any cash contribution to be paid to the National Transplant Trust Fund.

(b) The Internal Revenue Code is amended to account for the establishment of the National Organ Transplant Trust Fund.

(c) This act applies to taxable years ending after the date of enactment.

Sec. 4(a) A National Organ Transplant Trust Fund will be established in the Treasury of the United States and shall receive all amounts contributed by individual taxpayers. Funds in the Trust Fund shall be available for payment to the chief health officer of each state and to pay administrative expenses of modifying the individual income tax return forms and carrying out the operation of the Trust Fund.

Sec. 5(a) Each state shall establish an Organ Transplant Program in order to receive payments from the National Organ Transplant Trust Fund.

(b) States must use the funds to pay the costs of organ transplantation procedures and immunosuppressive drugs for eligible individuals. States may use not more than 5% of funds to publicize the availability of the trust fund and to solicit contributions.

(c) States will receive an amount proportionate to the contributions of their citizens to the Trust Fund. The Secretary of Health and Human Services shall certify a State as eligible for payments.

(d) The States shall determine the eligibility of individuals and shall also determine the medical expenses eligible for coverage.

(e) A state may not use money from the National Organ Transplant Fund to supplant funds normally made available by the State for organ transplantation assistance.

(f) A State may not use the money from the Trust Fund to satisfy a requirement for nonfederal contributions for participation in a program established under any other provision of law.

(g) Each state shall annually submit reports about its Organ Transplant Program to the Secretary of Health and Human Services.

(h) Definitions of "organ," "transplant procedure," and "State."

Sec. 6 Makes clear that this Act does not create any private right to sue by or on behalf of any eligible individual, and does not create an entitlement on behalf of any individual.

HARDIE G. CLIFTON
Heart Transplant: 12 September, 1984
Medical College of Virginia
Richmond, Virginia

On 2 July, 1984 Hardie entered Southern Maryland Hospital Center, diagnosis: Heart Failure.

After years of sitting in Emergency Rooms, Intensive Care Units, Hospital Rooms, and Coronary Care Units, we weren't too surprised when his cardiologist told us that a heart transplant was his only hope of survival. I was elated to know that there was still "hope" for Hardie.

I dealt with all the normal fears associated with a procedure as delicate as a heart transplant. I was mentally prepared for it. I wasn't prepared for the emotional, and financial battle that would ensue. I was not prepared for the rejection, and denials I would have to face.

Hardie's cardiologist contacted the Transplant Centers. Johns Hopkins wouldn't accept him, the one in Texas required a $50,000 deposit, and The Medical College of Virginia required a $30,000 deposit, because Maryland Medical Assistance (Hardie's only insurance coverage) would not pay for a heart transplant. MMA considered heart transplants to still be in the experimental stage, and therefore, would not pay for it.

When Hardie's doctor told me that MMA would not cover the cost of the transplant, I was a little shaken, but still very optimistic. We were American Citizens. I knew that The United States of America was the richest, most advanced Country in the World. I could not see where there would be a serious problem. My husband was dying because he needed a transplant, and I just knew that there had to be funds available for such things. Then came my rude awakening.

I started out by calling the various "help" organizations: The Heart Association, United Way, United Givers Fund, Red Cross, United Black Fund, etc.. I came up with zero. I was in a state of shock. I couldn't believe there was no help for us. I then turned to the news media. I got T.V., radio, and newspaper coverage. I set up a Heart Fund, at the bank, and prayed that people would respond. I continued to call organizations, and businesses, for help. My husband was dying, and I was no where near the $30,000 I needed. I then called the White House. I was later told that the White House contacted Governor Hughes (Maryland), he contacted the Governor of Virginia and guaranteed payment. Hardie was then, and only then, admitted to MCV. I had even gone to Redskin Park, and met with some of the Redskins to ask for their assistance. I had to knock on every door I saw. I will never be able to describe the hurt, and fear that I felt. I felt that my country had betrayed me. I thought of all the men, in my family, that had picked up guns and fought to defend our country. I thought of all the tax dollars my family had paid. I thought about all the sweat, and blood my forefathers shed, to help build our country. I just did not want to believe that my beloved country was going to allow my husband to die because "there were no funds available" to save his life.

It was my understanding that the Federal Government agreed to share the cost of Hardie's transplant with the State of Maryland 50/50. I don't know whether it was done that way, or not. All I know is, my husband was dying, ahd noone seemed to care. I had to yell, kick, scream, and scratch to get something done. By the time we got him to MCV, he was in such a deteriorated condition, they gave him less than 24 hours to live, and had no intentions of doing a transplant. I had to fight another battle down there.

I cannot see how the leaders of our country can approve a $500,000 renovation project, to house two (2) Pandas, and be willing to allow human beings to die because there is no money available for transplants. I would love to see the total dollar amount that has been spent on those pandas since they were given to us. I would not be surprised if it were up in the millions. I would love to know the dollar amount that is approved, and disbursed for Foreign Aid, while Americans are dying because of lack of medical care.

Hardie was just the 70th heart transplant done at MCV. I'm sure that heart transplants, and other organ transplants, are now being done on a weekly basis. States cannot carry this heavy financial burden. The Federal Government is going to have to pitch in, and help. The financial burden does not stop, when the patient is discharged from the hospital. A transplant recipient has a life-time of medical problems, emotional problems, financial burdens, and medical expenses.

I thank God I was strong enough to fight. Everyone does not have the same strength. I would not accept defeat. When one dooe would close in my face, I would knock on another one. I was determined that my husband's life would be saved. All during my ordeal, I was praying than no one else's loved one would have to go through with what I had to go through with. I was disabled, my husband was disabled, we had a child in school, our small income wasn't enough to cover our normal financial obligations, and here is someone telling me that I had to come up with $30,000 to get my husband admitted into a transplant center so he would have a chance to live.

I sincerely hope that Bill S.2409 will go through. I also hope that other measures will be taken to assist transplant recipients, and their families, after the transplant. We are faced with a lot of financial burdens, directly related to the transplant, that are not covered by a medicaid card. Your life is never the same.

MRS. SHERRY A. CLIFTON
11525 February Circle #201
Silver Spring, Maryland 20904
(301) 236-9077

TESTIMONY OF CONGRESSMAN DOUG WALGREN

BEFORE THE SENATE FINANCE SUBCOMMITTEE ON TAXATION AND DEBT MANAGEMENT

September 20, 1988

It is a pleasure and honor to appear today before you to testify today on a critical problem of our health care system -- how to pay for organ transplants.

I have introduced H.R. 5330, a companion bill to S. 2409 introduced by Senator Bumpers, which would create a checkoff on the federal tax return for taxpayers to direct any portion of their tax refund or a cash contribution to a National Organ Transplant Trust Fund. The Department of the Treasury would return to each state funds contributed by its citizens and each state would establish a program to help needy people pay for organ transplants.

The basic problem that this bill addresses is the fact that current insurance coverage of organ transplants, private and public, is inadequate. People today in many cases literally have to scrounge around for enough money to pay for transplants. Many of them even go to their congressman or senator -- even to the White House -- looking for help.

Patients with life-threatening conditions should not have to have bake sales and press conferences to raise money to pay for their medical care. Their survival should not depend on their political connections, where they live, or the generosity of their friends, family and neighbors. We should be able to find ways to pay for necessary medical care without impoverishing people. A compassionate country, as abundant in resources as ours, should not turn people away at the hospital door to die when they cannot pay for medical help.

Organ transplants today are terribly expensive and out of the reach of most people. The average liver transplant costs $135,000 to $238,000. The average heart transplant costs $57,000 to $110,000. For a heart-lung transplant, the average cost is $130,000 to $200,000. A kidney transplant costs, on average, $30,000 to $40,000. Coverage of transplants by private insurance policies is increasing, but usually the patient has to pay a share. Even if insurance covers 80% of the costs, that still leaves 20% of a $100,000 transplant or $20,000 for the patient to pay -- an amount usually out of the reach of most people. Medicaid coverage for the poor varies from state to state and is often inadequate with at least one state covering no transplants. Medicare, for the elderly, covers some -- not all -- transplants. After the initial operation, immunuosuppressive drugs, needed to make the transplant effective, can cost up to $5,000 a year, and very few insurance policies cover outpatient drugs. The result of this patchwork of health insurance coverage is that the bulk of the American people -- a broad swath of middle-income Americans -- are uninsured or underinsured for organ transplants and the financial burdens are crushing.

All of these costs often leave the institutions who perform transplants with the choice of turning the patient away or accepting the patient and incurring huge financial losses.

The best and the long-term solution is to improve the coverage of transplants under Medicare, Medicaid and private insurance. Congress has, in the case of Medicare, in which there is a direct federal responsibility, been strengthening Medicare's benefits. But we have a long way to go in providing comprehensive coverage for everyone.

Organ transplants represent the frontier of medicine and we must support it. Life can be extended and enhanced beyond our imagination through the ability to transplant organs and save lives. But this can occur only if we provide some support to allow these medical miracles to be pursued. In addition, we are strengthening our society by helping people return to the mainstream of life to become productive citizens. By building on this country's long-standing tradition of helping each other, we are also bringing attention, in this special field of medicine, to our common unity as human beings.

Testimony on S. 2409

the
Cooperative Organ Transplant Contributions Act
of 1988

by

Thomas E. Starzl, M.D., Ph.D.

Mr. Chairman, my name is Thomas Starzl, and I am Professor of Surgery and Director of Organ Transplantation Services at the University of Pittsburgh. I am pleased to present testimony before this subcommittee in support of S. 2409, The Cooperative Organ Transplantation Contribution Act of 1988.

This is a timely and compassionate measure which is truly needed to help many Americans gain access to, and benefit from organ transplant technology. Congress has done much to further the discipline of organ transplantation. In 1972 Congress passed the End Stage Renal Disease Program which guaranteed cost coverage under Medicare for any American needing dialysis or a kidney transplant. Furthermore, the National Institutes of Health have supported research efforts over the years which have both improved the efficacy of transplantation of all vital organs, and immunosuppressive drug therapy. This commitment has translated into life saving and life enhancing transplants for thousands of Americans — and has created a resource of scientific information, and research which will stop killer and disabling diseases that attack vital organs. The net result is that our citizens, the Nation's ultimate resource, have a new, and expanding, medical technology to preserve life. The benefits from organ transplantation and the accompanying immunosuppressive therapies are many, and, in the long run, will amortize the investment which this government has made in its people

Senator Bumpers' Bill, S. 2409, which is before this subcommittee, adds a unique and special feature for the development of organ transplantation. It follows a course already set by Congress in legislating the End Stage Renal Disease program, the National Organ Transplant Act of 1984, and subsequent amendments which improve our organ transplantation system. S. 2409 is new and special in that the proposed National Organ Transplant Fund is based on the generosity of the American people to voluntarily contribute to the effort. Nobody is taxed.

My testimony, Mr. Chairman will develop along the following lines.

I. History of kidney, extra renal transplants, and immunosuppressive therapies.

II. Payment for organ transplants, research and related issues.

III. The need for a National Organ Transplant Trust Fund.

I. History of kidney, extra renal transplants, and immunosuppressive therapies.

Mr. Chairman, I realize that his subcommittee deals with tax measures and not with medical procedures. You are concerned about S. 2409, and its effects on income tax strategies as a means to create a transplant fund. Therefore, I will submit a detailed article on the medical history of organ transplantation and immunosuppressive drug development as an appendix to this testimony. However, I will summarize some key facts which will be of interest to you and your colleagues.

A. As Chart I indicates, the numbers of organ transplants have increased dramatically from the period 1981 through 1987.

Chart I

Organ Transplantation Statistics
1981-1987

	81	82	83	84	85	86	87
Kidney	4,883	5,358	6,112	6,968	7,659	8,976	8,972*
Liver	26	62	164	308	602	924	1,182
Heart	62	103	172	346	719	1,368	1,441
Heart/Lung	5	7	20	22	30	45	41
Pancreas	-	35	61	87	130	140	180**

Source: Health Resources Services Administration, Division of Organ Transplantation, Department of Health and Human Services.

* The slight decrease is due to the limited supply of donated kidneys. S. 2409, among other things, will help educate Americans to become organ donors.

** estimated

B. This is due to several factors:

1. Increased research and, therefore, greater efficiency in all areas of organ transplantation.
2. Increased development of immunosuppressive, or anti-rejection drug therapies.
3. Greater awareness on the part of primary physicians that organ transplants are life saving techniques which can help their patients.
4. Greater awareness, and willingness on the part of the American people to become organ donors.

C. Survival rates for all transplant patients are increasingly higher. This is due to improved transplant techniques and continuous development of immunosuppressive drugs.

D. Organ transplantation is not a parochial feature of American medicine. It is international in scope, and has the potential to lead America, and our world, into the 21st century of medicine.

II. Payment for organ transplants, research and related issues.

Any new medical technology begins in a pioneer stage, and organ transplantation, along with immunosuppressive drugs is no exception. The struggle is always to move from an "experimental" or "innovational research" stage to an on-line medical therapy that becomes part of our national health care system which needy Americans have access to and support for. This has been the odessey for organ transplantation in America.

A. End Stage Renal Disease Program (ESRD).

In 1972 Congress enacted the ESRD program which established kidney dialysis and transplants as an entitlement program under Medicare for any American needing or opting for either treatment. Prior to that, funding for these relatively new procedures were sporadic, and dependent on research grants, responsive third party payers, or individual ability to pay. Once passed, however, the numbers of transplants steadily increased.

Chart II

Kidney transplants, by Medicare coverage: 1973-85

	Total		Medicare coverage[1]			
			Medicare		Non-Medicare	
Year	Number	Percent change	Number	Percent change	Number	Percent change
1973[2]	1,600	—	—	—	—	—
1974	3,190	—	—	—	—	—
1975	3,730	+16.9	—	—	—	—
1976	3,504	-6.1	—	—	—	—
1977	3,973	+13.4	—	—	—	—
1978	3,949	-0.6	—	—	—	—
1979	4,271	+8.2	—	—	—	—
1980	4,697	+10.0	—	—	—	—
1981	4,885	+4.0	4,421	—	464	—
1982	5,358	+9.7	4,917	+11.2	441	-5.0
1983	6,112	+14.1	5,616	+14.2	496	+12.5
1984	6,968	+14.0	6,029	+7.4	939	+89.3
1985	7,895	+10.4	7,073	+17.3	803	-35.8
			Average annual percent change			
1973-85	—	+8.3	—	+12.5	—	+6.8

[1] Break out of patients by Medicare entitlement was not captured until the 1981 End Stage Renal Disease Facility Survey.

[2] 1973 data cover the period July 1 through December 31; Medicare end stage renal disease coverage was effective July 1, 1973. The overall rate of growth is therefore calculated from 1974. For Medicare and non-Medicare transplants, the rate of growth is calculated from 1981.

SOURCE: Medicare Health Insurance System counts: 1973-75. Social Security Administration, Bureau of Health Insurance: Data from the End Stage Renal Disease Facility Survey Tables, 1976-77. Health Care Financing Administration, Bureau of Data Management and Strategy: Data from the End Stage Renal Disease Facility Survey, 1978-85.

The limiting factor on kidney transplants was, and continues to be, the availability of cadaver kidneys. Even so, the ESRD program, and its kidney transplant aspect, is very expensive. Low estimates for a kidney transplant fall into the $30,000 to $35,000 range. Add on an average of $5,000 for immunosuppressive treatment a year and the expense becomes clear.

But the Congress has made the commitment to the program, and will continue to fund it through taxes while looking at ways to make it more cost effective. There is little doubt that the benefits are great -- transplant recipients, freed from dialysis can lead productive lives and, among other contributions to society, become non dependant tax payers.

B. Payment for Extra Renal Transplants

Payments for extra renal organ transplants, such as livers and hearts, has been very much like a patch-work quilt.

If a transplant patient is a member of a generous insurance program, he or she may be covered. However, if a patient belongs to an Health Maintenance Organization (HMO), which emphasizes low cost health care, chances for transplant coverage would be slim. Again, if a Medicaid eligible patient in need of a transplant lived in a state with a high per capita income, he might be covered. But not all state Medicaid programs cover organ transplants. A patient with an end term liver or heart disease who receives social security disability payment may be covered. But the patient must meet the two-year "wait" period before he can receive Medicare benefits and could well die before those benefits take effect. Still other patients may have inadequate benefits or none at all, and not gain access to a transplant center due to this. Such families and patients are often forced to engage in public fund raising to obtain the money needed for a transplant.

Chart III

Cost Estimates for Organ Transplants
1986

Kidney	$ 30,000 - $ 40,000
Liver	$135,000 - $238,000
Heart	$ 57,000 - $110,000
Heart-Lung	$130,000 - $200,000
Pancreas	$ 30,000 - $ 40,000

Source: Health Resources and Services Administration
Division of Transplantation, Department of
Health and Human Services

a. Medicaid

Medicaid is the shared cost program between states and the federal government which provides health insurance for individuals who meet certain poverty income criteria. By statute, the federal government follows a cost sharing formula with states which ranges from a minimum of 50% to a maximum of 80%. The formula is determined by per capita income within a given state. States have greater flexibility to cover different health care procedures, but they must conform to general federal criteria such as covering procedures which are "reasonable and necessary" for eligible beneficiaries.

As far as liver and heart transplants go the trend has been towards increasing coverage, as Chart IV indicates. The general rule of thumb has been that states with greater per capita income have been more willing to fund transplants while those with lower per capita income and a lesser Medicaid resource are not. Some patients, then, become victims of geography and either forego the transplant or are forced into public fund raising for the procedure.

But there is another twist in Medicaid assistance. In order to meet eligibility requirements, a family or patient must meet "spend down" requirements or, in effect, divest themselves of assets. This is often a harsh requirement, but families and patients in need of a life saving organ transplant are often desperate, and will take any step needed to gain assistance. S. 2409, if passed, will go a long way to relieve the humiliation and desperation which patients face when seeking financial assistance.

b. Medicare

As noted Medicare pays for all kidney transplants and immunosuppressive drugs up to a year after the patient leaves the hospital. Medicare support for other transplants is quite limited

In 1983, as a result of an NIH Consensus Conference on liver transplantation, the Department of Health and Human Services agreed that Medicare would pay for liver transplants for children (under 18) suffering from Billary Atresia and other rare congenital effects. While this appeared to be a step forward, it really was an empty gesture. Few, if any, children under 18 could meet social

Chart IV

Comparison (August 1986 and January 1988) of State Medicaid Coverage of Selected Transplant Procedures

State	Bone Marrow		Heart		Heart-Lung		Liver		Pancreas	
	8/86	1/88	8/86	1/88	8/86	1/88	8/86	1/88	8/86	1/88
TOTAL	41	44	24	31	15	14	33	37	6	8
Alabama		X						X		
Alaska	X	X								
Arizona *	X	X	X		X		X			
Arkansas										
California	X	X	X	X	X			X		
Colorado	X	X	X	X	X	X	X	X		
Connecticut		X	X	X	X	X	X	X		
Delaware	X	X		X			X	X		
Dist. of Columbia	X	X	X	X			X	X		
Florida	X	X								
Georgia	X	X					X	X		
Hawaii	X	X								
Idaho	X	X								
Illinois	X		X	X		X	X	X	X	X
Indiana		X	X	X	X		X	X	X	
Iowa	X	X		X			X	X		X
Kansas	X	X								
Kentucky	X	X	X	X			X	X		
Louisiana	X	X	X	X		X	X	X		
Maine	X	X	X	X			X	X		
Maryland	X	X	X	X	X	X	X	X		
Massachusetts	X	X	X	X	X	X	X	X		
Michigan		X	X	X	X	X	X	X		X
Minnesota	X	X	X	X	X	X	X	X	X	X
Mississippi	X	X								
Missouri	X	X	X	X			X	X		
Montana		X		X				X		
Nebraska	X	X		X			X	X		
Nevada	X	X					X	X		
New Hampshire		X						X		
New Jersey	X	X	X	X			X	X		
New Mexico	X	X	X	X	X	X	X	X		
New York	X	X	X	X	X	X	X	X		
North Carolina	X	X		X		X		X		
North Dakota	X	X	X	X		X		X		X
Ohio		X	X	X	X	X	X	X	X	X
Oklahoma	X	X					X	X		
Oregon *	X		X		X		X			
Pennsylvania	X	X	X	X	X	X	X	X		X
Rhode Island	X						X			
South Carolina	X									
South Dakota	X	X								
Tennessee	X	X		X			X	X		
Texas	X	X		X			X	X		
Utah		X					X	X		
Vermont	X	X		X						
Virginia	X							X		
Washington	X	X		X			X	X		
West Virginia	X	X	X	X	X		X	X	X	
Wisconsin	X	X	X	X			X	X	X	X
Wyoming										

* Non-coverage has been challenged in the courts.

Source: American Council on Transplantation, based on data from the Health Care Financing Administration, Department of Health and Human Services.

security disability requirements which would trigger Medicare benefits after a two year waiting period.

Medicare has moved forward in covering adult heart transplants. Based on special studies, the Health Care Financing Administration (HCFA) which manages Medicare, agreed to pay for heart transplants based on the following criteria:

1. Patients must be carefully selected based on critical need and likelihood of success.
2. Patients must be managed according to specific protocols
3. The transplants can only be performed in designated centers which have met specific success rates*

To date HCFA has designated 20 centers for heart transplantation and has paid for about 60 transplants.

The Committee must remember that, again, the heart transplant patient under age 65 must meet the social security disability criteria of the two year wait before becoming eligible for Medicare benefits. Cardiomyopathy, one of the worst of the heart killer diseases which can be defeated by a transplant, is not very patient or concerned about Medicare eligibility requirements.

Chart V

One Year Survival Rates for
Selected Organ Transplants
1986

* Kidney - Patient Survival	93%
Cadaver	85%
Living Related	90%
Liver	80%
Heart	85%
Heart-Lung	60%
* Pancreas - Patient Survival	80-85%
- Grafts	55%

Sources: * University of Pittsburgh, Unpublished data, 1988.
Batelle Institute, Unpublished data, 1988.
Department of Health and Human Services.

At present, Medicare does not cover adult liver diseases, although a study on the effectiveness of these transplants is being conducted by the Office of Health Technology Assessment in HHS. We would hope that the results of this study will be released in a timely fashion. But even if Medicare agrees to cover adult liver transplants, the same social security disability two-year waiting obstacle remains. Medicare currently does not cover heart-lung transplants or pancreas transplants.

c. Private Insurance Coverage

Private insurance programs vary greatly in their coverage. A large insurance company will generally write a coverage program for what a client wants. Large corporations usually have generous insurance benefits for employees and their families.

In 1981 few private insurance companies covered extra renal transplants. These were viewed as "experimental" or "innovational research." Each large insurer has its own medical department to periodically assess and review medical procedures with a view to coverage or non-coverage. Thus, one insurance company may afford generous coverage, while another may not cover transplants at all. Most private third party payers look to, and follow, Medicare coverage as a norm for procedures they will pay for. Happily, the private sector has proved to be more flexible in transplant coverage than the government.

The Committee must remember, however, that even generous coverage for organ transplants usually meets 80% of costs. This can leave a substantial debt burden on a family or patient which can be economically crippling. S. 2409 can prove to be immensely helpful in assisting those, as well as many other transplant patients and their families.

d. Private Fund Raising

I'm sure, Mr. Chairman, that you and your colleagues in the Senate are well aware of appeals for help from families with children, or adult members, needing transplants. Those who have no insurance or who are underinsured or who are not eligible for any federal assistance are forced to "go public" and engage in fund raising. I can tell you from direct experience that these are desperate ventures which take a frightful psychological toll on families and patients.

They are, literally, forced to advertise a dying child, or adult to the public in hopes that out of compassion, the public will respond.

Some families are quite successful and do obtain funds needed for transplant. These are, for the most part, put into a trust which is managed by a local church, bank, or voluntary organizations such as the Children's Transplant Association, the American Liver Foundation, or Heart Assist.

Mr. Chairman, over the years I have seen Americans from every corner of this great country respond to the needs of families with members needing transplants. But many others have been overlooked, not because our people don't care or are less generous in different parts of our country -- but because not all families know what to do, or where to turn for help. A family in a rural, less affluent part of the nation with a child needing a liver transplant can easily be passed by because the area is too poor, or they don't know where to turn.

S. 2409 would go a long way to help transplant patients such as these.

e. The Uninsured

It is estimated that 64.4 million Americans have no insurance to cover heart transplants while 3,900 in that group may need one in a given year. Another 61.2 million individuals lack any coverage for liver transplants while 2,471 may need one.*

Some feel that the answer to this problem is Medicaid. But there are already disturbing trends in this area. Oregon and Arizona, which have covered heart and liver transplants in the past, have stopped this coverage. Virginia is considering a similar move.

These states feel that limited Medicaid resources should be spread over a variety of lower cost health needs of eligible beneficiaries. This is an ominous trend, and certainly makes a case for S 2409.

* Evans, Roger W., "Transplant Coverage: A Public Policy Dilemma," Business and Health, Washington, D.C., April, 1986, P. 6.

III. The need for a National Organ Transplant Trust Fund and Passage of S. 2409.

Mr. Chairman, the major reasons for establishing such a trust fund by means of Senator Bumpers' proposed Bill have already been put forward in my testimony, but I would like to summarize them at this time.

A. Congress, Through the End Stage Renal Disease program funded by Medicare has already established an entitlement program for patients needing kidney transplants. Thousands of Americans have benefitted from this program, and it is logical that Congress follow through and help Americans needing other vital organ transplants.

B. The current public and private sources for funding extra renal transplants are erratic and conditional. Depending on where one lives, where on works, what kind of insurance one has one might or might not get a life saving transplant. Senator Bumpers' Bill would rationalize the payment system by creating a fund to meet the needs of transplant patients who lack coverage from other sources. The fund would also assist patients who are underinsured, and rescue them from an all but bankrupt status brought on by attempting to save the life of a loved family member needing a transplant. The fund would also relieve those transplant patients who face uncertainties over the supply and payment for immunosuppressive drugs needed to prevent organ rejection.

C. Organ transplant techniques are developing at a rapid pace as are immunosuppressive drug treatment. More and more physicians and patients are aware of its life saving potential. By establishing the proposed Trust Fund we are truly investing in our own nation.

Successful transplant patients move back into the main stream of American life and enjoy their lives, their families, and contribute to society around them.

D. Organ Transplantation along with its associated immunosuppressive drug treatment is on the cutting edge of medicine. It's effects save and enhance individual lives, but its wider effects, including ongoing research, contribute to the whole of medicine. The fund, which would be set up to help individuals gain access to transplantation has a double effect of moving transplant technology forward in ways that will benefit all Americans and all of Medicine.

E. The proposed Bill is workable. I noted in my testimony that many transplant patients go public to raise needed money. That money, literally millions and millions of dollars, pours in from all over the nation, from rich and poor alike who come to the aid of a fellow American in need. Senator Bumpers' Bill sets a national target. Rather than helping a special transplant patient in one town or city, Americans would have a specific way to help many in need. The check off system proposed by the Bill whereby a citizen can add to his tax bill or take less on a tax refund to build the trust is a clear and simple way to help others. We Americans are pretty good at helping one another. This Bill gives all of us a chance to do this.

Mr. Chairman, all of us are aware of the fact that this is a tax subcommittee and that tax matters are your concern. But this proposed Bill should please you and all your colleagues. It allows you the opportunity to raise money to help Americans without raising taxes!

You and your colleagues recently passed a Catastrophic Insurance Bill to help older Americans. The Bill is to be funded mainly by contributions from the beneficiaries themselves. That is a good strategy, Mr. Chairman, because it, again, allows Americans the opportunity to help themselves. Senator Bumpers' Bill does the same, but in a different way. Establishing the trust is a first step in a new direction. Many tell us that we must reduce health costs because our tax supported programs are limited. Well, Mr. Chairman, S. 2409 isn't a tax bill and it isn't limited. It calls upon the generosity of the American people -- and that's an unlimited resource. I urge you and your colleagues to move Senator Bumpers' Bill forward as rapidly as possible.

Thank you, Mr. Chairman. I'll be pleased to answer any questions you may have.

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International Gazette

The development of whole organ transplantation

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[illegible] by Research Grants from the Veterans Administration and Project Grant No. [illegible] from the National Institutes of Health, Bethesda, Maryland

The success of whole organ transplantation has been one of the least predicted events in the history of medicine. In 1961, the Nobel Laureate Burnet wrote in the New England Journal of Medicine that "much thought has been given to ways by which tissues or organs not genetically and antigenically identical with the patient might be made to survive and function in the alien environment. On the whole, the present outlook is highly unfavorable to success. . ."[1]. This pessimistic view was published only a year before the avalanche of successful clinical renal transplantations in 1962 and 1963 that extended such procedures beyond the occasional identical and fraternal twin cases of the mid and late 1950s.

Within and outside of the medical establishment, the frenzied pace of developments in 1962 and 1963 dismayed and dumbfounded critics, many of whom were unaware of what had been accomplished already. In the spring of 1964, an editorial beginning with the word 'Cannibalizing' was published in the Annals of Internal Medicine questioning again the inherent feasibility of these efforts as well as the ethical basis[2]. Responses in an ensuing issue including a letter by me reflected a spectrum of views held by basic and clinical investigators[3]. By the summer of that year, I published a detailed account of our experience[4] in which the majority of kidney recipients had achieved long survival with social and vocational rehabilitation. However, these developments were already late in a long, but at first slowly unfolding, story.

The earliest beginnings

Heterotransplantation. – The first clinical efforts at renal transplantation predated the water-shed years of 1962 and 1963 by half a century. The first known attempts at clinical renal transplantation by vascular anastomoses were made without immunosuppression between 1906 and 1923 with pig, sheep, goat, and subhuman primate donors. Jaboulay of Lyon[5] and the German Unger[6] made the first of these foredoomed efforts, but others followed as summarized elsewhere[4]. None of the kidneys functioned for long if at all and the human recipients died from a few hours to nine days later.

Although the trials were carried out with little or no understanding that there was a biologic barrier to success, some principles were clearly delineated. The applicability of vascular suture techniques, and even the possibility of using pelvic implantation sites were either envisioned or actually practiced. No further clinical renal heterotransplantations (animal to man) were tried again until 1963 when systematic and surprisingly successful clinical trials were made with chimpanzee[8] and baboon[9] kidneys. Little noted at the time or subsequently were attempts at chimpanzee to human heart transplantation by Hardy with intraoperative death[10] and transplantation of 3 chimpanzee liver heterografts[11, 12, 13] of which 2 behaved indistinguishably from homografts[11, 13]. The eventual death of all of the recipients of animal organs ended heterotransplantation trials for 15 years until Bailey's baboon to human heart transplantation[14].

Homotransplantation. – The first human to human kidney transplantation (homotransplantation) was reported in 1936 by the Russian Voronoy[15] who transplanted a kidney from cadaver donor of B+ blood type to a recipient of 0+ blood type in violation of what have become accepted rules of tissue transfer[4]. The fact that the donor had been dead for 6 hours further precluded hope of success. The recipient died 48 hours later without making urine. Although the possibility that there would be an immune barrier to success was not obvious to most early clinicians, Voronoy perceived this problem, although imprecisely. A more complete understanding awaited the classical studies of Medawar with rodent skin grafts which established the immunologic basis of rejection[16].

In the 20 years following Voronoy's case, sporadic further efforts at renal homotransplantation were made without effective immunosuppression as documented by Groth[7]. The heterotopic extraperitoneal technique of renal transplantation which became today's standard was developed by the French surgeons Dubost[17], Kuss[18], and Servelle[19] and their associates. John Merrill, the Boston nephrologist, had seen the extraperitoneal operation while travelling in France in the early 1950s as was mentioned by Hume et al[20]. This technique was adapted for the historically important identical and fraternal twin cases in Boston[21, 22]. Variations of the operation shown in Figure 1 are used today worldwide.

As isolated results, none of the foregoing efforts, or even all put together, would have had major significance. The principal ingredients of organ transplantation, namely immunosuppression, tissue matching, and organ procurement (and preservation) were either unknown or so undeveloped that grafting of the kidney at a practical level was only a dream. Extension of transplantation beyond the kidney was beyond imagination. No trace can be found in the literature of transplantation of extrarenal organs until the mid 1950s when Welch described auxiliary (heterotopic) liver transplantation[23], and when Willman and Hanlon[24], and Shumway[25] showed the technical feasibility of heart transplantation. Transplantation of the pancreas which had been used as a physiologic preparation by Houssay[26] was revived in the experimental laboratory in 1960 by Lillehei et al[27]

Thus, the astonishing developments in transplantation of all these organs became a story of the last quarter century. I will provide here some reminiscences of this era and speculate about how the momentum of this progress can be sustained and accelerated. Such hopes derive in part from the seminal contributions already made by the pharmaceutical industry and from the revolutionary changes in drug development that have expedited the search for better drugs to combat rejection, prevent ischemic injury to tissue, and change other pathophysiologic events during or around transplantation. The most specific of these inquiries has been with immunosuppression

Immunosuppression before SANDIMMUNE® (cyclosporine)*

By 1960, the possibility of weakening the recipient immune system in order to mitigate rejection had been established in animals with corticosteroids[28], total body irradiation[29,30], and the cytotoxic drug 6-mercaptopurine[31-34] or its imidazole derivative, azathioprine[35]. Sporadic attempts to use these techniques for renal homotransplantation in humans were so unsuccessful[7,22,36,37,38] that it was widely thought that the immunosuppression requisite to prevent rejection would inevitably lead to immunologic invalidism and lethal infections.

Double-drug therapy with azathioprine and steroids

Renal transplantation became practical in 1962 and 1963 with the marriage of corticosteroid therapy (prednisone or prednisolone) to baseline therapy with azathioprine[4,39]. This synergistic drug combination, the value of which was immediately confirmed[40], permitted fundamental observations to be made, including the fact that rejection was a reversible process (Figure 2). With the passage of time after renal transplantation, a change in the relation between the graft and the host often occurred, permitting eventual reduction of drug doses (Figure 2). Patients who did not require chronic high-dose corticosteroid therapy to retain their grafts have been able to return to useful social and vocational activities for as long as 25 years. The double-drug therapy with azathioprine and prednisone remained the gold standard of transplantation for many years.

However, consistently good results could be obtained only with transplantation from blood relatives, and even then only with good tissue matching (see later). This unsatisfactory situation was a great stimulus to the search for better immunosuppressive regimens.

Triple-drug therapy

Consequently, modifications of or additions to the original double-drug treatment were made as summarized elsewhere[41] during the next 16 years. Most of the modifications were designed to blunt the attack of the lymphocytes, which had been recognized as the mediators of rejection. The most significant addition was antilymphocyte globulin (ALG) which was used as an adjunct to azathioprine and prednisone[42]. The ALG consisted of polyclonal antibodies raised in horses, rabbits, goats, or other animals by immunizing them to human lymphocytes[11]. When thymic lymphocytes were used for immunization, the product was called antithymocyte globulin (ATG). The active gamma globulin was extracted, purified, and made ready for intramuscular or intravenous use. Usually, the ALG was administered during the first few weeks or months after transplantation.

In spite of its great potential value, polyclonal ALG was not universally employed as a part of the anti-rejection armamentarium because of severely limiting features including its inability to be standardized. This latter problem as well as other deficiencies were eliminated with the hybridoma technology introduced by Kohler and Milstein[43]. With hybridoma cells injected into the peritoneum of mice, a homogeneous (monoclonal) antihuman-lymphocyte antibody could be produced. Therapy with monoclonal antibodies was introduced into clinical medicine by Cosimi et al[44], using the so-called OKT3 antibodies which selectively deplete mature T-lymphocytes. Their prime objective was to reverse kidney graft rejection that was non-responsive or poorly responsive to conventional corticosteroid therapy and azathioprine. OKT3 therapy has been proved to be of value clinically and it was released in 1986 for general use in the United States by the Food and Drug Administration (FDA).

In spite of what had been achieved by 1978 with most of the foregoing drugs and drug combinations, whole organ transplantation remained an unpredictable and dangerous undertaking especially if cadaver donors were used. The margin between effective and toxic immunosuppression was too narrow. Although the feasibility of transplanting the human liver[45,46], heart[47,48], lung[49], and pancreas[50] was established in 1967 and 1968, the results were too poor with any of these organs to justify broad application. Consequently, the field of transplantation had a relative growth arrest throughout the 1970s, and there seemed to be little hope of major improvement. The clinical transplant sessions at scientific society meetings had become tedious expositions in which claims of results, counterclaims, and shuffling of details of management filled the programs. The boredom was shattered with the arrival of cyclosporine (SANDIMMUNE).

The SANDIMMUNE era

The immunosuppressive qualities of this fungus extract were delineated by Borel et al[51] of Switzerland, and the first clinical trials for solid organ transplantation were carried out by Calne and his associates in Cambridge, England, beginning in the spring of 1978[52,53].

Renal transplantation

In Rome during the first week of September 1978, the International Transplantation Society held its biennial meeting. The members were granted an audience with the newly proclaimed Pope John Paul I whose short tenure sadly ended little more than a month later. Encouragement of the Catholic church for the transplantation community was forthcoming from Pope John Paul along with a reminder of the attendant social and moral responsibilities. The timing of the support and advice could not have been more appropriate since the first clinical trials with SANDIMMUNE for renal transplantation were reported from Cambridge during that week, along with an impressive array of data from several research laboratories. The magic of a possible new era was in the air. The stages of drug development by the Sandoz Pharmaceuticals Division had been a model of scientific accuracy and completeness. The chemical structure and physical qualities of the drug were completed long before Borel et al published studies of its immunosuppressive potency, and Borel had established dose effect relationships in several autoimmune models as well as after skin grafting in rodents[51].

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* The editor has replaced the author's references to cyclosporine by SANDIMMUNE, the registered trademark for the cyclosporine product (outside USA, Canada and Holland SANDIMMUN)

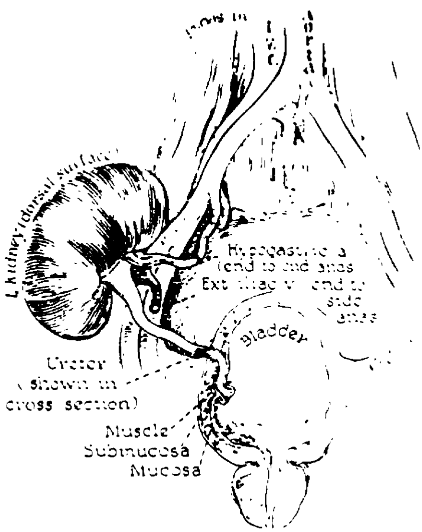

Fig. 1 Renal homograft (By permission of JAMA 187 734 1964)

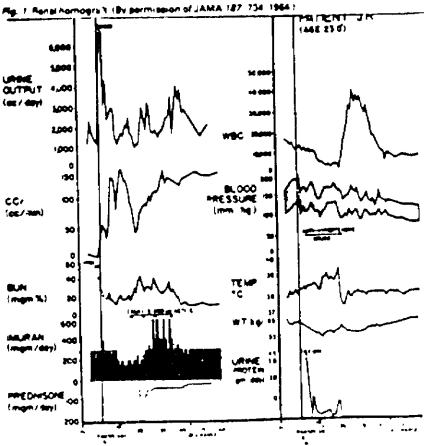

Fig. 2 [illegible] 117 385 [illegible]

Fulfillment of the dreams of that Italian autumn was not automatic. There was a high mortality in the 1978–79 trials at Cambridge, using SANDIMMUNE with other drugs and Calne et al recommended that SANDIMMUNE be used alone for future trials[43] The most encouraging notation was that a number of the recipients had achieved chronic function of transplanted kidneys, livers, or pancreases without steroids However, nephrotoxicity was observed universally, and 3 of the first 34 Cambridge recipients developed lymphomas The complications of SANDIMMUNE used with other agents were even more severe in further English trials by Sweny et al[44] who recommended abandonment of the new drug

United States trials of renal transplantation with SANDIMMUNE were begun in late 1979 at the Peter Bent Brigham Hospital in Boston and at the University of Colorado, Denver. Disappointing results, no better than with azathioprine and prednisone were reported from the Peter Bent Brigham Hospital using SANDIMMUNE as the sole drug for the first 2 postoperative months[45] The case accrual in Boston was slow, and only 16 patients had been treated with SANDIMMUNE by September 1981, almost 2 years later.

The other and far more encouraging American trial was begun at the University of Colorado and continued at the University of Pittsburgh, systematically combining SANDIMMUNE with steroids in cadaver kidney recipients[46] The ability to control rejection of cadaver organs with this drug combination was greatly improved compared to any therapy in the past[37] Of equal importance, the maintenance steroid doses generally were low enough to allow survival without cosmetic deformity and other unacceptable morbidity By late May 1980,

Table I Slide presented at ASTS in late May 1980, discussing the predicted impact of cyclosporine which we had been using with steroids in Denver since late 1979

Strategy of transplantation

1 Use of living donors will be obsolete
2 Role of tissue matching will be reduced
3 Importance of preformed antibody analysis will be increased
4 Avoidance of sensitization will be important.
5 Diabetics will be easier to treat
6 Candidacy criteria will be liberalized
7 Dialysis/transplantation interface will be drastically altered
8 Organ supply will become critical

we had treated more than 40 renal recipients, and with this experience, I prepared a slide for a forum discussion at the American Society of Transplant Surgeons about where transplantation was headed. That slide is reproduced verbatim in Table I. All of the predictions have come true, at least in part.

The International Transplantation Society next met in Boston on 2 to 5 July 1980 during the American national holiday celebrating independence. The advocates of SANDIMMUNE slightly outnumbered the detractors, but by now two more American trials of SANDIMMUNE and steroid therapy for renal transplantation had just begun or were planned in Minneapolis[58] and Houston[59] exploiting the policy of polypharmaceutical therapy advanced in the Colorado-Pittsburgh trials. With this approach, employing drug combinations with additive or synergistic immunosuppression, the doses of individual agents usually could be kept in the non-toxic range. SANDIMMUNE and steroids also have been combined in later years with azathioprine, and polyclonal or monoclonal ALG (OKT3).

The swift dissemination of all of the information, good or bad, about SANDIMMUNE was done with great responsibility on an almost weekly basis from Basel and from the American Sandoz headquarters in East Hanover, New Jersey. Further information was exchanged at international meetings held in September 1981 in Cambridge[60] and in May 1983 in Houston[59]. By the first of these occasions, extensive data had been compiled about transplantation of extrarenal organs, and by the second, SANDIMMUNE was almost ready to be released by the Food and Drug Administration (FDA) for general use in the United States. When this release came in November 1983, there was a generally high degree of understanding about how the drug should be used, its side effects, and the expectations of graft and patient survival.

One strong recommendation, if not absolute condition, of the FDA was that SANDIMMUNE administration should be carefully guided by monitoring blood levels of the drug. This necessitated the introduction in clinical pathology laboratories worldwide of new and sophisticated radioimmunoassay (RIA) or high performance liquid chromatography (HPLC) techniques developed in Basel by the Sandoz scientists.

By the time SANDIMMUNE was released, there was a better understanding of the so-called lymphomas which had been seen by Calne et al[61], Sweny et al[62], and us[63-65]. Similar lymphoproliferative tumors, earlier called reticulum cell sarcomas, had been seen frequently under azathioprine-steroid therapy with or without ALG[67]. It was realized in the patients treated with SANDIMMUNE that these lesions probably were caused by Epstein-Barr virus infections[54,56,62,66]. The conventional wisdom until 1983 was that once the resulting B cell lymphomas became monoclonal they had achieved malignant autonomy and were beyond cure[52].

Curiously little thought had been given to the obvious expedient of stopping or lightening immunosuppressive therapy. When this was done, most of the lesions melted away quickly without regard for clonality[64]. The implications of these events for an improved understanding of host-tumor relationships is considerable, but at a practical level, the observations have removed the specter of a high SANDIMMUNE mortality caused by *de novo* lymphoid malignancies.

Transplantation of vital extrarenal organs

Because hepatic transplantation is the most difficult of all the grafting procedures, it is almost incongruous that the liver has always been the first extrarenal organ to which improvements in management have extended from the kidney experience, or from which advances have tracked back to the kidney. The reason was that those working with me or with Roy Calne in England on drug development or other aspects of transplantation had a lifetime passion to extend what was learned with the kidney to the even more difficult ultimate objective of liver replacement (Figure 3).

My own first efforts at liver transplantation were begun at Northwestern University in Chicago in the summer of 1958[65]. In Boston during the same summer, Francis D. Moore independently had begun a systematic exploration of the same possibility[66]. The young English surgeon, Roy Calne, came to Harvard in 1960 where in the course of his research with immunosuppressive drugs[15] he was exposed to Moore's work. Calne visited Chicago before he returned to England. I can remember his courteous manner, his determination to see everything that was going on, and his quick intelligence. Time has not dimmed these wonderful qualities.

Efforts to mitigate liver rejection in dogs with irradiation of either the donors or recipients failed completely[67]. Efforts with azathioprine were more successful[66,68] and truly long survival was achieved by the mid-1960s using azathioprine[69] and ALG[41]. The first clinical efforts at liver transplantation were made at the University of Colorado in Denver in 1963[3], but the first unequivocal successes were not until 1967[11,69]. Today the longest survivor in the world is a young woman who is married to a United States marine stationed in Okinawa. She is in her eighteenth postoperative year.

In 1968, Calne began his pioneer English program of liver transplantation[70] and before long he established a fruitful collaboration with Roger Williams, the extraordinary hepatologist at King's College, London[71]. For many years, these single American and English programs shared the vicissitudes and sorrows of defeats more common than victories. In all that time, I never heard or saw Calne utter or write a bitter or complaining word. It was fitting that the first 2 liver recipients treated with SANDIMMUNE were his patients[33].

The advent of SANDIMMUNE changed liver transplantation from an exotic experimental procedure to a patient-service, tripled survival after that operation[41,72,73] (Figure 4), paved the way for more effective transplantation of the heart[74,75,76], and made possible the previously unattainable objectives of transplanting the heart and lungs[77] or single lungs[78]. The extraordinary change that had occurred was already reflected in the published collection of papers about extrarenal organ transplantation from the Cambridge symposium[60] in September 1981.

The crystal ball

The intellectual and pragmatic harvest made possible by SANDIMMUNE goes on. However, the search for improved immunosuppression merely has been intensified by what has been accomplished. New drugs are being evaluated even now of which some are even more potent than SANDIMMUNE. One example is the experimental drug, FK 506 which was de-

THOMAS E STARZL MD PhD born in Le Mars Iowa, USA, in 1926 is Professor of Surgery at the University of Pittsburgh Medical School Pittsburgh Pennsylvania USA 25 years ago he performed the first successful cadaveric kidney transplantation Since he has continuously contributed to the science and art of transplantation and applied this knowledge in order to improve patient care His innovative work with transplantation of the liver has been even more singularly outstanding After 10 years of experimental work he performed the first successful liver transplantation in 1967 Since moving from University of Colorado Medical School Denver to Pittsburgh in 1981 he has led the development of one of the world's most successful multiple organ transplantation programs More than anyone else Dr Starzl has contributed toward the concepts and practice of multiorgan transplantation

One would be to improve the infusion approach by introducing novel ingredients into the solution which stays in the cold devascularized organ during storage, or by using agents to minimize the reperfusion injury after revascularization in the recipients During the last decade, various mediators of the inflammatory response have been implicated in ischemic and postischemic injury Furthermore some of these mediators as well as their inhibitors have been synthesized in pharmaceutical research An important mediator which is thought to be central to a wide range of pathologic processes is platelet activating factor (PAF)[91, 92] A PAF-Inhibitor (PAF-I) has been developed by the Sandoz Pharmaceuticals Division [93, 94] and is being tested for its ability to reduce ischemic injury amongst other effects Although numerous other specific possibilities could be cited, efforts to foresee history in detail would be inappropriate in what is a historical perspective

The second broad possibility could be improved continuous perfusion, either at normal or cold temperatures With the remarkable sophistication that has characterized research in artificial organ development, it is amazing that continuous perfusion techniques today offer so little more for organ preservation than they did two decades ago

Tissue typing

Twenty-five years ago when the modern era of transplantation was in its infancy, it was predicted that tissue matching would have to be perfected if grafting procedures were to succeed In 1964, the first efforts were made by our Colorado transplant group, working with Paul I Terasaki of the University of California, Los Angeles (UCLA) to prospectively select ideal related or non-related donors for specific renal recipients based on relatively primitive antigen matching[illegible] The results were disappointing Since then, the validity of tissue matching, its genetic basis, and above all its complexity have become increasingly recognized The value of tissue matching for transplantation between family members has been established beyond any doubt

However the very complexity of the human histocompatibility system has militated against easy matching between non-related people Thus, at a practical level, close matching for transplantation of the cadaver kidney has become less and less of a consideration, especially since the availability of better immunosuppressive regimens made possible by SANDIMMUNE With transplantation of the liver, heart and other extrarenal organs, tissue matching has not even been taken into consideration because the events leading to and connected with transplantation occur so quickly and often with such urgent recipient needs that a labored search for a well-matched organ is not possible The somewhat surprising conclusion has been that good results can be obtained even with completely mismatched cadaver organs This fact has reduced progressively the emphasis on antigen matching

However none of the immunosuppressive measures available today can prevent the immediate destruction of kidneys by preformed humoral antibodies in what has been called 'hyperacute rejection In 1965, Terasaki, Marchioro, and I[96] described the first example of this phenomenon Kissmeyer-Nielsen et al[97] of Denmark, Williams et al[98], and numerous other observers have added to an understanding of hyperacute rejection Kidney transplants are the most subject to hyperacute rejection, but the heart and liver in that order of susceptibility also can be similarly destroyed The process of destruction is caused by thrombotic occlusion of the graft microvasculature and consequent devascularization[illegible] Hyperacute rejection can be avoided usually but not invariably by the so called crossmatch test which detects antidonor antibodies in the recipient serum in advance of operation. The crossmatch has proved to be the single most important contribution of tissue typers to the practice of transplantation during the last quarter century[101].

It is possible that the effector cascade set into motion by humoral antibodies can be aborted by pharmacologic intervention One of the most interesting and promising possibilities was recently reported by Makowka et al[102] who used the PAF-I mentioned earlier in connection with organ preservation to delay the hyperacute rejection of pig kidneys which are normally destroyed by preformed heterospecific antibodies within a few minutes after transplantation to dogs The same drug can prevent the hyperacute rejection of heterotopic heart grafts transplanted to rats presensitized with heart donor strain skin grafts[103], and if potent conventional immunosuppression was added, long survival followed[104].

The new options versus old values

Developments in transplantation and artificial organ technology have changed forever the philosophy by which organ-defined specialties such as nephrology, hepatology, and cardiology are practiced Until recently, what could be offered victims of vital organ failure was a rear guard approach designed with diet, medicines, or surgical procedures to extract the last moment of life-supporting function from the failing organ Now, and for the first time in human history, the breathtaking possibility has emerged when all else fails of starting over with an organ graft, or (in the not too distant future) with a manufactured organ Much of the groundwork for this revolution was laid in the pharmaceutical industry The consequences of changing human ecology are well known to those who have studied the amplifying effects of antibiotics on the population explosion that is said to threaten the earth or at least the quality of life of its inhabitants It remains now to be seen how society will manage transplantation, the most recent product of its creativity and sponsorship

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STATEMENT BY

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Mr. Chairman, I am honored to appear before your subcommittee today to testify on behalf of S. 2409, The Cooperative Organ Transplant Contributions Act of 1988. I would like to begin by making a few introductory comments about my background in the transplantation field and the work being performed at Baylor University Medical Center in Dallas, Texas.

When I became a doctor of medicine in 1975, I vowed to tend and heal the sick to the best of my ability. Little did I consider the problem of the cost of health care, having been raised and received my education in Sweden, with its system of socialized medicine.

Perhaps fate led me to choose my specialty -- transplant surgery. In 1979, I was given the opportunity to study transplantation under Professor Thomas Starzl in Denver, Colorado. Not only did I receive training in liver transplantation, but I gained insight into a different economic system -- including the economics of health care in the United States.

In 1979, liver transplantation was but a human experiment because of its complexity and overall difficulty. In those days, only two truly active liver transplant units existed in the world; one in Denver and one in Cambridge, England. In the United States, the main funding for these operations was provided by the National Institutes of Health. Over a period of several years liver transplantation was performed on only a few individuals, thereby allowing for the development of technique and understanding in this specialized field.

The experimental status given to liver transplantation disappeared almost overnight when new and improved medication to prevent rejection of the transplanted liver was introduced in March 1980, when the first liver transplantation in the United States using Cyclosporine was performed by Dr. Thomas Starzl. Suddenly the results, that is survival following liver transplantation, were as predictable as those of kidney transplantation. In June 1983, a consensus conference under the auspices of the National Institutes of Health declared that liver transplantation was not experimental but, in fact, appropriate treatment for certain disorders. The same conclusion was reached by the Congressional Task Force on Organ Transplantation, which delivered its recommendations in June 1986.

Now, instead of specializing in a field which only recently was regarded by many as experimental research, I find myself delivering medical care to an ever increasing number of patients who are dying from disorders not curable by "conventional" means. The patients are young, averaging just over 40 years of age, with families to support and care for. Instead, these men and women are dying. They suffer from many different diseases such as primary biliary cirrhosis or sclerosing cholangitis -- disorders where the immune system has misfired and attacks the person's own body, in this case the liver. Some suffer from inborn diseases such as Biliary Atresia, which is an absence of bile ducts. Others suffer from different forms of hepatitis contracted from blood transfusions received during previous operations (such as gallbladder or coronary bypass). And health care professionals -- doctors, nurses, technicians -- have been infected while treating and caring for sick patients or while trying to find a remedy for infectious hepatitis.

These patients come to Baylor and other qualified transplant centers with the hope of saving their lives. As a result of the tremendous strides that have been made in medical research and patient care over the years, I am confident that if allowed to perform the necessary surgery and treatment we can help save the lives of more than 86% of those people (BUMC 1985 to 1988 average). The rate of success with our patients at Baylor has proven that. However, we are not always given that opportunity.

Approximately 35 million people, or 17% of the U.S. population, do not have private insurance coverage. And for those who have some type of medical insurance, not all of those policies provide coverage for liver transplantation. In addition, a growing number of insurance companies are placing unrealistic caps on transplant related expenses, making these policies look good to the consumers, but in reality providing inadequate benefits to cover an actual transplant. If patients do not have insurance, they must raise the necessary funds using every means imaginable. I think most of us have seen the extent to which patients, families and whole communities have had to go to scrape together enough money for someone in need of a liver transplant. The alternative, <u>if</u> it is available, is to submit to a new, unproven program where the patient may be offered a "free liver transplant" in order for the new liver transplant program to be tested and "brought into the market place."

Baylor has provided at least $1.2 million of its own budget in uncompensated care to help offset the cost of transplants for medically indigent patients. Yet, 28 patients have been rejected as candidates for liver transplantation due to lack of funding (187 patients have been transplanted). However, most indigent patients never even get that far, since their referring doctor or the institutional doctors turn down the possibility of referral because of the obvious lack of monetary resources.

The irony is that the cost of dying from liver disease is close to, if not equal to, the cost of having a transplant. The total average charge today for a liver transplant at Baylor University Medical Center is $98,000. However, Medicare or the patient's insurance pays for expensive conventional therapy but not transplantation. Today, one does not die of a failing liver at home. One dies in the intensive care unit in a hospital.

Roger Evans, Ph.D., Senior Research Scientist at Battelle Human Affairs Research Centers, calculated that in 1986 the average cost of upper gastrointestinal bleeding was $18,000 per episode. (R. Evans, Issues In Science And Technology, Spring 1986, p. 95.) Usually the patient who needs a liver transplant goes through several such resource intensive complications before dying. Thus, for approximately the same cost, we can either bury the patient or have him or her leave the hospital as a functioning citizen, able to support and care for his or her family.

At this juncture, I cannot overemphasize the importance of appropriately and properly administrating any and all funding programs for transplantation. As a doctor and as director of the transplant program at Baylor University Medical Center in Dallas, one of my greatest concerns about any measures affecting liver transplantation is the critical issue of control of funds by less informed bureaucrats who might impose DRGs or other similar dollar saving measures. My concern over this is so great that I seriously considered not supporting any legislation affecting this field, as I am convinced these dollar-slashing programs could destroy liver transplantation just as dramatically as the medication Cyclosporine made it viable.

For example, kidney transplantation has experienced significant reductions in reimbursable charges, making it impossible for the transplanting centers to break even on these cases. With the adjustment due next month in October 1988, deep cuts will be made into the substance of the program. The DRG system will severely impact the quality of care and jeopardize these kidney transplant patients. In my view, if DRGs were to be applied to liver transplantation, lives would be lost. And <u>that</u> is the real bottom line. Hairbrained cost cutting measures imposed by bureaucrats would cause deaths of some of these patients. In dollar terms alone this would be very costly, since there is no more expensive care than attempting to transplant a liver and later lose the patient because our hands were tied by silly regulations.

Mr. Chairman, I do not know of any nation that can afford to deliver all possible medical care to every patient in need. The taxes that would necessitate this would strangle any economy. So how do we as a nation meet the economic challenges of what transplant technology has brought us? I firmly believe S. 2409 provides some real answers to that question. Senator Bumpers' bill would provide for a check-off on the federal tax return and establish a National Transplant Trust Fund -- the fund being "fed" by the voluntary contributions of taxpayers. Each state would, in turn, receive monies which have been donated by their citizens from the National Transplant Trust Fund. The funds would be used to help defray the cost of life saving surgery and treatment for patients in need of organ or bone marrow transplantation. And by administrating the program at the state level, funding would go directly toward patient care. By using such a mechanism, no heavy or expensive administration is needed, no new burdensome regulations are warranted. Such a system would not burden the federal or state budget and would eliminate the pressure to create funding for these therapies within the Medicare system.

Liver transplantation is extremely difficult and complex, but if done well, as we have shown at Baylor, I believe the results justify the cost.

In conclusion, Mr. Chairman, I am grateful that I have been given the opportunity and the time to share my support for this important piece of legislation. In these days of severe budget restrictions and cost cutting measures, the legislation which Senator Bumpers has introduced is imperative and innovative. S. 2409 would provide a mechanism for funding transplantation for patients without increasing taxes and, more importantly, without creating a myriad of regulations through the Department of Health and Human Services or other federal agencies such as the Health Care Financing Administration. The citizens of this nation have proven time and again their desire and willingness to help others in time of critical need. S. 2409 provides the opportunity for all of us to respond to a dilemma in our health care delivery system. If this bill is approved and implemented, sensible use of such funds will fill a true need in modern American health care.

I strongly urge your committee to report S. 2409 so that this bill may be given favorable consideration by the full Senate.

Thank you.

COMMUNICATIONS

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October 13, 1988

Ms. Laura Wilcox
Hearing Administrator
Senate Finance Committee
SD-205
Washington, D.C.

Mr. Ed Mihalski
Minority Chief of Staff
SH-203
Washington D.C. 20510

Gentlemen:

You have requested comments regarding proposed legislation authorizing a tax refund credit to establish a National Organ Transplant Trust Fund. At the onset, let me note that I am an educated professional who is capable of approaching the issue of organ transplants on a very academic plane. (See for example, my article that was published in the Journal of Family Law in 1973 entitled "Blood Test Exclusion Procedures In Paternity Litigation: The Uniform Acts and Beyond" which explored the use of tissue typing techniques developed in transplant surgery in paternity litigation.) However, your press release requires that my comments be brief (no more than ten pages typed) so I have taken a more succinct, (albeit, tongue in cheek,) approach to make my point.

In October 1971, I participated in the University of Illinois Renal Transplant Program by donating a kidney to my sister. In November, 1971, I received a bill for approximately $1500 from the University of Illinois Medical Center for my efforts. It never seemed right to me that I should be charged for the transplant operation. After all, the hospital hadn't helped my condition. In many respects, I had been more help to them by reducing the costs they were incurring by keeping my sister in their dialysis program. Besides, in those days, I simply couldn't afford to pay. Prior to the transplant surgery, my sister's illness had completely sapped my family's income and savings. I had managed to advance my education but without significant parental financial aid, I had to rely on part-time employment, scholarships, and student loans to finance most of my studies. Therefore, when I got this bill in 1973, paying it simply wasn't feasible. (Unless I wanted to default on my student loans - which I didn't do.) So, I went to the surgeon who performed the operation and asked her what to do. She looked at the bill, laughed, and said, "Just throw it away, we'll figure out some way to pick up the tab."

A few years later, I asked her how they had taken care of those expenses and she said, "I'm not sure but nowadays, social security absorbs the cost." In those days, that seemed fine by me.

Well, now many years have passed. Thanks to the marvels of modern medicine, my sister and I are both in good health and are working hard as a teacher and a lawyer to fund social security payments for our parents so they can continue to live in the suburban home they have bought and paid for, play golf, and continue their lifestyle as the king and queen of the Dupage County Illinois Republican dinner circuit. (At age 76, my dad still manages to get re-elected as a Township Trustee - I think they will abolish township government in Illinois before they abolish him.)

Suddenly, though, I have reached a stage in life where I'm beginning to have misgivings about using the social security fund to cover transplant costs. It is clear to me that if social security is going to fund this endeavor, they must structure the system to accurately reflect (i) the sky rocketing costs associated with transplant surgery, and (ii) the fact that my parents and all their friends have seemingly vowed to remain senior citizens until their children (and perhaps their grandchildren) have died of old-age. Somehow, I have my doubts that the actuaries have dealt with these factors effectively, so as a conscientious taxpayer, I feel I have only three options to pursue at this junction;

(1) I can renounce my U.S. citizenship, forego my vested social security benefits, and move with my wife to the British Virgin Islands, where we can live on a beach eating coconuts and fresh fish. In the process, of course, we would leave our three sons with their grandparents who could continue to provide for them and fund their advanced education with their social security payments. (My wife likes this one.)

(2) I could continue to support programs that increase social security taxes until they have reached a point where wage withholdings eliminate all take-home pay and provoke most middle-aged Americans to burn up their organ donor cards and declare war on the grey panthers,

(3) I could support your efforts to enact a tax refund credit specifically geared to fund transplant costs and hope that most Americans will kick in at least a dollar or two each year in much the same way that they do for the presidential campaign fund and wildlife fund to help address this problem and relieve some of the financial burdens on our social security system. I might even be able to use my contact in the advertising world to help promote the credit concept.

Of course, I realize there is no perfect solution to this dilemma. Nonetheless, of these three approaches, the tax refund credit seems most attractive. But if you can't pass the legislation, I may be forced to consider one of the first two alternatives.

Good Luck. The ball's in your court.

Respectfully submitted,

Mark E Larson, Jr.

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