2004

Assessing The Impact Of Public Awareness Promotional Campaigns On Organ Donation In The United States

Stuart J. Katz

Recommended Citation

Katz, Stuart J., "Assessing The Impact Of Public Awareness Promotional Campaigns On Organ Donation In The United States" (2004). *Seton Hall University Dissertations and Theses (ETDs)*. 529.
https://scholarship.shu.edu/dissertations/529

Assessing the Impact of Public Awareness Promotional Campaigns on Organ Donation in the United States

Stuart J. Katz
Spring 2004
Seton Hall University, South Orange, NJ
Thesis Advisor: Monsignor Dennis Mahon

Acknowledgements

I would like to thank Msgr. Dennis Mahon for his feedback and assistance, Dr. Don Lombardi for welcoming me back to Seton Hall after a lengthy leave of absence, my mother, Karole, for helping me understand the statistical analysis, and my wife Beth, for her support and patience during this process.

Table of Contents

Introduction

The first successful, human, solid organ transplant was performed in 1954, when one identical twin donated a kidney to his brother who was dying of kidney failure. Organ transplantation truly burst into the public consciousness in December, 1967, when the first heart transplant was performed in Cape Town, South Africa. Many ethical, moral and religious questions arose, but the medical facts stood – it was scientifically feasible to recover a solid organ from one person and utilize it to extend the life of someone else.

The early efforts in organ transplantation were hampered by the human body's powerful immune system. The organ recipient's body treated the transplanted organ as if it was a dangerous infection, and the immune system would rapidly "reject" the organ. The frustration of physicians and patients was exacerbated by the fact that while the surgical techniques worked well, the immune response of rejection meant certain failure. Steroids and a drug called azathioprine provided limited immunosuppression for kidney recipients, but people in need of other organs had little hope of long-term survival post-transplant.

In 1983, the evolution of solid organ transplantation began with the US Food and Drug Administration approval of cyclosporine, the first drug shown to suppress the immune system in a way that significantly reduced the chances of rejection for kidney, heart, and liver recipients. Once the rejection problem had been addressed with great success, organ transplantation rapidly evolved into a medical specialty that saves thousands of lives every year. But with further advances in surgical techniques, and even more potent anti-rejection drugs added to the therapeutic mix, another problem began to emerge – the lack of available organs for transplant.

The numbers of Americans awaiting a life-saving solid organ transplant currently stands at about 85,000, and 16-17 people die every day in the US while waiting. The organ donor shortage is considered to be a public health crisis, with public and private resources used in a wide range of programs and activities designed to increase the number of donors, reduce the transplant waiting lists and save lives.

"Organ donor awareness" is the term that is used most frequently to categorize efforts to encourage the general public to donate organs. Over the past 10 years, local, regional, and national groups, government agencies, pharmaceutical companies, and many other entities have worked to promote organ donation, but the waiting list in the US grew by an average of nearly 11% annually between 1993-2002. (OPTN, 2004a) Have any of these efforts been successful? If these campaigns were not undertaken, would the waiting list have grown more rapidly? Could the funding for organ donor awareness activities be directed toward another aspect of the transplant process that might prompt a greater improvement in reducing waiting lists? These are the fundamental issues we will review in this project.

Glossary of Terms and Abbreviations

(adapted from organization web sites when possible)

ACOT: Advisory Committee on Transplantation, a group of about 40 experts in various disciplines within organ transplantation formed to advise Secretary of Health and Human Services Tommy Thompson on issues relating to government policies affecting organ transplantation.

AOPO: The Association of Organ Procurement Organizations, professional society of those involved in the operation and administration of OPOs.

AST: The American Society of Transplantation (AST) was founded in 1982 and is an organization of more then 1,800 transplant professionals dedicated to research, education, advocacy and patient care in transplantation.

ASTS: The American Society of Transplant Surgeons, similar to AST but membership is primarily comprised of physicians.

DOT: The Division of Transplantation is a sub-group of the US Health Resources and Services Administration of the US Dept. of Health and Human Services. Responsibilities include Federal oversight of contracts for the Organ Procurement and Transplantation Network (OPTN), the Scientific Registry of Transplant Recipients (SRTR), and the

National Marrow Donor Program (NMDP); national coordination of organ donation activities, and the funding of research grants to increase organ donation.

LRD: Living-related donor – such as a brother donating a kidney to his sister, or a mother donating part of her liver to her son, etc.

NHBD: Non-heart beating donor, an organ donor who has ceased cardiac function, generally considered to be not as viable as a donor with heart function but no brain activity (brain-death).

NOTA: The National Organ Transplant Act of 1984, signed by President Ronald Reagan, that approved funding for the OPTN and brought the federal government into the growing number of entities involved in organ transplantation.

OPO: Organ procurement organization, non-profit, regional groups that are responsible for managing and coordinating the allocation of available organs in a defined geographic area.

OPTN: The Organ Procurement and Transplantation Network (OPTN) is the unified transplant network established by the United States Congress under the National Organ Transplant Act (NOTA) of 1984. The act called for the network to be operated by a private, non-profit organization under federal contract.

PSA: Public service announcement, a television, radio, or print ad placed with donated time in support of a cause or non-profit organization.

UNOS: The United Network for Organ Sharing, a federal government contractor agency that is responsible for administration of the national organ transplant waiting lists. UNOS has held this contract since 1986 and has never been seriously challenged for its renewal.

Chapter 1 – Research Questions

As a valid therapeutic option for patients suffering from end-stage organ failure, solid organ transplantation offers the hope of extending, and in many cases transforming the lives of transplant recipients and their loved ones. Patient survival rates – the foremost measurement of transplant success – have increased over the past decade, with 5 year survival for a kidney transplant recipient currently estimated at 85% - in other words, if you received a kidney transplant tomorrow, there is an 85% chance that you would live 5 more years. (OPTN, 2004b)

The unfortunate reality of the organ transplant system in the US today is that despite the most advanced surgical techniques, anti-rejection drugs, and highly skilled medical practitioners for every step in the transplant process, the number of people waiting for a solid organ transplant continues to outpace the number of available organs. Between 1993-2002, the national organ transplant waiting list increased by an average of nearly 11% per year, (OPTN, 2004c) while the number of deceased donors between 1993-2003 increased an average of 2.8% per year. (OPTN, 2004d) In 2001, the number of living organ donors surpassed the number of deceased donors for the first time. (OPTN, 2004e)

While there are many reasons offered for the growth in waiting lists and the slower growth in deceased donation, significant efforts to increase organ donation are conducted every year by variety of groups ranging from high school service clubs to the US government. One major component in these efforts has been that of increasing awareness of the benefits of organ donation and the severe shortage of organs available for transplant. Celebrities who have received organ transplants appear on television, public service announcements are broadcast nationwide featuring emotional appeals from transplant families, government officials at all levels make pronouncements about the need for more donors, and Hollywood gets into the act with major motion pictures about organ transplantation such as *Return To Me* and *John Q*.

The research question seeks to analyze the largest efforts to increase organ donor awareness and assess their benefit when positioned against the statistical realities of organ transplant waiting lists. The primary question is: what impact, if any, have major national organ donor awareness campaigns conducted over the past 10 years had on the actual level of organ donation in the United States? Would organ donation rates be lower if not for the time, expertise, and financial resources devoted to promoting donor awareness during that time period? To evaluate those questions, we conducted an attitudinal survey using a Likert scale on two groups:

Group 1 – general public consisting of the author's friends, acquaintances, fellow students, and randomly selected others who have no regular involvement in, or contact with the profession of organ transplantation, generated through e-mail contacts

Group 2 – Transplant professionals (physicians, nurses, transplant coordinators, procurement specialists, pharma industry) who spend 100% of their time in organ transplantation. This list was gathered from subscribers to, and listings in The 2003

International Transplant Directory (Warren, 2003) that is essentially the "yellow pages" of organ and tissue transplantation.

The survey assessed the familiarity with organ donor awareness campaigns and their perceived effectiveness in increasing the likelihood of future organ donation.

Subsidiary Questions

Since the general topic of "increasing organ donation" has been the subject of numerous studies on issues such as definitions of brain death, use of marginal donors, and ethical issues in living donation, we are limiting our research and evaluation to the primary question noted above and a brief analysis of the following subsidiary question:

Has the federal government's recent initiative to increase organ donation, conducted by the US Dept. of Health and Human Services since Tommy Thompson became Secretary of HHS yielded positive results?

Limitations

We are not researching specific methods that can be used to increase organ donation. There are many federally funded research projects currently in progress that are investigating every aspect of the organ donation process, from determining the best person to make the request, to organ transportation protocols, to the creation of donor registries.

We are not researching the effectiveness of specific techniques in increasing organ donor awareness. The studies noted above must include such data as part of their grant renewal applications.

We are only dealing with life-saving, solid organ transplants – not blood, bone marrow, corneas, or other tissue. Many parallel initiatives are in progress to increase donation of these components, and the federal government is focusing its current effort primarily in increasing solid organ donation. The author has 15 years of experience in communications issues in solid organ transplantation, so maintaining specificity to this area in this project is optimal. (see Appendix A)

Chapter 2 – Historical Review

Solid organ transplantation stands today as an evolving testament to the efforts of countless researchers, physicians, nurses, and early transplant patients who were willing to take significant risks in the hope of saving their lives and the lives of others. Transplantation is also a business, offering high-priced products and services. The average cost of a liver transplant today is about $250,000, with additional expenses before and after the surgery pushing that cost to over $300,000. (ALF, 2003) Anti-rejection drugs must be taken for the duration of the patient's life, and many other medications are involved in the long-term treatment of a transplant recipient. Many recipients need medications costing $10-20,000 every year.

Despite the costs, solid organ transplantation has proven to be an economically and medically beneficial treatment for the most serious illnesses. For example, patients with severe kidney disease who would be on dialysis for 12-15 hours a week just to maintain a reduced level of activity can return to work full time after a successful kidney transplant. Many heart recipients who were unable to endure anything that would increase their heart rates prior to a transplant are back at school, work, and exercise, and remaining an active member of their families. The author has personally interviewed hundreds of organ transplant recipients and family members of organ donors and their stories are the strongest argument for organ donation.

According to the UNOS on-line databank on 10/14/03, there were 240 hospitals performing kidney transplants, 140 centers for pancreas transplants, 123 hospitals for liver transplants, 140 heart transplant centers, 70 hospitals performing lung transplants, and 45 centers for intestinal transplants. These numbers are not cumulative as many hospitals perform more than one type of organ transplants. Smaller numbers of centers within these groups perform multi-organ transplants, such as heart-lung, or kidney-pancreas, and a different subset exists for living donor transplantation.

The financial scope of organ transplantation in the US runs quickly into the billions per year when including the costs of surgeries, hospital stays, pre- and post-operative testing, medications, physical and occupational therapy, and related expenses. Due to the specialized nature of transplant medicine, many large health insurance companies have established specific business units devoted to the care and long-term treatment of organ transplant recipients. The largest of these groups, United Resource Networks, notes on their web site that:

> "United Resource Networks provides over 3,000 indemnity carriers, reinsurers, managing general underwriters, third-party administrators, stop-loss providers, HMOs, employer groups and other payors with access to the nation's leading transplant network for their members or their clients. The Transplant Network, Transplant Access Program, and Extra Contractual Services provide clients with a single source for transplant benefit management." (URN, 2004)

The vast majority of Americans support organ donation – 81% according to a 1999 poll (Pew, 1999), yet those waiting for a transplant still face frightening odds. A detailed examination of key milestones and issues during the 50 years of organ transplantation illustrates the unique nature of transplant medicine and key factors that helped create the current situation facing people in the US in need of a life-saving solid organ transplant.

The 1950s – The Early Days

The potential for transplanting organs from one person to another has intrigued physicians for many years. Though there were numerous experiments with the procedure in animals in the early 1900s (Carrel, 1914), it wasn't until 1933 that the first human kidney transplant was reported by a Russian physician. (Hamilton, 1984) The human body's powerful immune system presented a significant challenge, as the transplanted organs were attacked rapidly and powerfully as foreign invaders. Physicians understood this response, and sought ways to prevent it or limit it. One approach was the use of a living-related donor, where genetic similarities between donor and recipient would minimize the rejection response. In 1952, surgeons Michon and Hamburger performed the first living-related kidney transplant in Paris, with a mother donating a kidney to her son. The procedure was not considered successful because the transplant rejected after just 22 days. (Michon, 1953)

In Boston, MA, Dr. Joseph E. Murray, who had performed kidney transplants on over 100 dogs, suspected that rejection could be avoided if the donor and recipient had exactly the same genetic makeup. (Knox, 1997) In December 1954, Dr. Murray got the opportunity to test his theory when 23 year-old Richard Herrick was suffering from end-stage renal failure. His identical twin Ronald agreed to donate one of his kidneys. As his colleagues, the media, ethicists, and others with serious kidney diseases awaited the outcome, Dr. Murray performed the first successful kidney transplant.

Since the transplanted kidney came with the identical genetic code as the one that stopped functioning, the immune system essentially shrugged and ignored the new organ as an original part. Richard Herrick was able to celebrate his place in medical history for over eight years. His body never rejected the transplanted kidney – he died of a heart attack. (Gahrton, 1990)

This medical milestone started the modern era of solid organ transplantation, providing hope to people with serious illnesses, creating a growing medical specialty, and pushing the limits of the human body to withstand surgical interventions.

The 1960s – The Wonder Years

After the success of Dr. Murray's kidney transplant, many other physicians, scientists, and researchers achieved significant breakthroughs that would push organ transplantation further away from science fiction and closer to clinical viability.

The first immunosuppressive compound was 6-mercaptopurine, developed by chemist Gertrude Elion. In various animal tests, 6-MP was shown to suppress the immune response to foreign tissue, offering a chance to extend the surgical success of transplantation beyond the operating room.

Research into the transplantability of other major organs also generated many successes in the early part of the decade. Dr. Thomas Starzl was diligently working on techniques for liver transplantation - in dogs in 1960, (Starzl, 1960) and for the first time in humans in 1963. (Starzl, 1963) The early attempts at human liver transplantation were not considered successful – the longest survival time among the first 7 patients was just 23 days. (Starzl, 1996)

Interest in heart transplantation was also increasing, again with significant work in animal models. Dr. Richard Lower and Dr. Norman Shumway were investigating the optimal methodology for transplanting hearts, using mixed-breed dogs. Their research reinforced the notion that by suppressing or modifying the immune response, the length of organ function and patient survival would likely increase. (Lower, 1960)

Kidney transplant research in the early 1960s featured advances in modifying immune response. Total body irradiation (TBI) was used in combination with 6-MP to extend graft survival up to 18 months with a kidney transplant from a non-related donor by Dr. Rene Kuss. (Kuss, 1962)

A derivative of 6-MP called azathioprine was showing an ability to mediate the immune response, alone or in combination with steroids. These findings supplemented the research on matching techniques between donor and recipient that would also reduce the speed and severity of organ rejection episodes. Blood type and human leukocyte antigen (HLA) typing and matching offered a better chance for success. Early research in these areas included computer analysis of human antibodies, development of new preoperative tests, and in 1964, the first prospective clinical trial to use HLA matching in donor selection. (Donor Foundation, 2003)

While there were many significant scientific advances in organ transplantation during the 1960s, nothing captured the world's attention like the first human heart transplant, performed on December 3, 1967. Surgeons in the US and several other countries had completed enough experimental heart transplants in animals to make them feel that they were ready from a technical perspective to attempt a human heart transplant. Many moral and ethical questions remained, but Dr. Christiaan Barnard, a South African surgeon who also trained in the US, decided that he had the right recipient, an appropriate donor, and the strength to withstand the media frenzy that would ensue.

Louis Washansky, a 53 year old grocer, was truly at the end of his life in the cardiac ward in Groote Schuur Hospital in Cape Town, South Africa. When Denise Darvall, a 25 year old bank clerk was struck by a car and suffered irreparable brain damage, Dr. Barnard matched their blood types and knew that he had a potential donor for Washansky. Her father agreed to donate her organs, and 9 hours later, the breakthrough procedure was complete. (Groote Schuur Hospital, 2003)

The news coverage generated by this procedure was massive considering that this was long before 24 hour cable news channels and the Internet. There were also ethical outcries, and even charges that Dr. Barnard's ego - not medical science – drove the decisions throughout the process. Louis Washansky lived only 18 days, dying from bilateral pneumonia (Hoffenberg, 2001), but the perceived success of his transplant opened a dramatic new chapter in the history of medicine.

The 1970s - Fighting Rejection

Though surgical techniques allowed physicians to move solid organs from one person to another and connect them successfully, the powerful immune mechanisms of the human body presented a formidable barrier to any long-term transplant success. During the 1970s, transplant specialists spent a great deal of time investigating optimal combinations of drug-based immunosuppression, pre-transplant body irradiation, and refining techniques to test and match organs between non-twin donors and recipients. While there were a few notable advances, such as the first successful lung transplant (Derom, 1971), the biggest scientific advance in transplantation to date was under study in a lab at Sandoz Pharmaceuticals in Basel, Switzerland. Sandoz encouraged employees to bring soil samples back from their vacations in various parts of the world so that they could be analyzed and studied for potential pharmacologic activity. Dr. Jean Francois Borel, a biologist, was given a fungus sample collected from a barren Norwegian hilltop. Intrigued with the potential antibiotic activity of an agent called cyclosporine that he was able to isolate, the product moved through the earliest stages of research, but was not a business priority for Sandoz at the time. Meanwhile, Dr. Borel discovered that the compound had the ability to selectively inhibit a key biological mechanism that led to organ rejection. (Borel, 1976) Even with this exciting news, Sandoz management at the time told Borel to cease his work on the compound and as he noted in an interview, "pour it down the drain." (Katz, 2003)

Fortunately for transplant recipients, Dr. Borel did not accept that order. In fact, he secretly continued testing the drug, even taking it himself to prove it could be absorbed successfully in the bloodstream. (Katz, 2003)

With enough evidence to regain management support to continue development, the next step was finding a transplant specialist who would believe in the compound enough to try it with patients. British transplant pioneer Roy Calne saw the potential of this compound and after a number of successful tests in animals, began using it in his transplant patients in 1978. The early results were very positive (Calne, 1979) – and Sandoz now realized the commercial potential of this product and helped physicians expand the trial usage so that there would be sufficient data to gain regulatory approval to market the drug. While the research efforts continued, many patients were gaining a significant extension of their lives through the use of this innovative medication.

The 1980s – The Cyclosporine Era

The development of cyclosporine was rapidly changing organ transplantation in the early 1980s. By using cyclosporine instead of existing anti-rejection drugs like azathioprine and steroids, longer survival of the transplanted organ and of the patient was likely. There were also studies that combined the new, still unapproved cyclosporine with existing drugs to work toward a "cocktail" that would provide maximum benefit while managing sometimes serious side-effects. (Starzl, 1980)

On the surgical front, the first successful heart-lung transplant was performed at Stanford University Hospital in 1981, on a 45 year old woman. (Reitz, 1981)

It's important to note that the definition of "successful" for most of the breakthrough events on organ transplantation is survival after the surgery for a period greater than 6 months. Though Dr. Christiaan Barnard performed the first heart transplant in 1967, his first successful heart transplant was performed in 1968. If an organ is connected, functions briefly in the operating room, and then shuts down, causing the death of the patient, that is not considered to be a successful transplant.

On November 14, 1983, Sandoz Pharmaceuticals received notice from the US Food & Drug Administration that they had successfully obtained approval to market a drug with the active ingredient of cyclosporine under the brand name Sandimmune. (FDA, 1983) The drug was only available as an oil-based liquid that was usually mixed with orange juice or chocolate milk by the patients when they took it. The 14 years from Norwegian soil sample to approved prescription drug saw the work of thousands of researchers and physicians, and the trust of many early patients pay off. The first immunosuppressant approved for use in kidney, liver, and heart transplantation would help spur the dramatic growth of solid organ transplantation in the US, as the most complicated problem facing physicians and their patients – organ rejection – now had a potential solution. Studies of intermediate-term effects of cyclosporine use among patients who were participating in clinical trials were generally positive and encouraged a rapid uptake of the new drug. In one study, cyclosporine treated patients had longer survival, longer graft survival, and fewer acute rejection episodes than patients on a regimen of azathioprine and steroids. (Merion, 1984) The science of immunosuppression was essentially transformed by one drug, saving patients as well as pushing scientists to find more potent compounds.

Another experimental transplant that drew attention and controversy was the first animal to human infant xenotransplant in 1984. At Loma Linda University Medical Center, a premature infant known only as Baby Fae, was born with an underdeveloped heart. Without a transplant, she would die in a matter of days. Dr. Leonard Bailey, who had performed numerous cross-species animal transplants, felt that Baby Fae didn't have enough time to wait for a deceased donor transplant, as her cardiac function was severely impaired. With the authorization of the hospital's review board, he took a heart from one of his laboratory baboons and implanted it in the 12-day old infant. The preliminary results seemed promising as the infant regained the skin color associated with full heart function. The media machine was in high gear. As the hospital notes:

> "Night after night, newscasts around the world showed the baby wiggling, yawning, and "talking" to her mother on the telephone. The millions of people whose hearts Fae touched were heartbroken when she died November 15, 1984, from complications that caused her red blood cells to clump together, obstructing microcirculation throughout her body." (Loma Linda Med. Ctr., 1999)

As many in the medical community suspected, the significant complications related to xenotransplantation had not been resolved. The ethical firestorm that followed included calls for Dr. Bailey's arrest, stinging editorial criticism in medical journals, and questions about the accuracy of the consent form signed by Baby Fae's parents. (Stoller, 1990) Today, 20 years later, xenotransplantation is still an experimental science with no routine clinical use.

There were other interesting surgical advances later in the decade, including the first successful transplant of the entire abdominal organ bloc that included the liver, stomach, pancreas, duodenum, small intestine, and colon. The operation was performed on a child with short-gut syndrome and liver failure, and the patient survived over 6 months. (Starzl, 1989)

The first living-related, split liver transplant was performed in 1989 by Dr. Christoph Broelsch at the University of Chicago. Taking the left lobe of the liver from a mother and transplanting into her daughter, Dr. Broelsch opened a new pathway for those with serious liver diseases that would probably not survive the lengthy wait for a deceased donor liver donation. Other benefits seen from this surgery were the improved functionality of tissue taken from a living donor, and the potential for a better quality of immunologic match from a parent. (Broelsch, 1990)

As the 1980s came to an end, the science and business of solid organ transplantation were starting to merge. The surgical viability of kidney, heart, and liver transplants and reasonably effective anti-rejection medications combined to bring transplantation to the forefront of many scientific, cultural, and financial discussions. The next decade represented a great opportunity for all involved in transplantation, but as many found out, success can bring about problems as well.

The 1990s – Growing Pains

The last decade of the century got off to a fast start with regard to solid organ transplantation. According to UNOS statistics, there was a 12.4% increase in the number of transplants performed in 1990 vs. 1989 (OPTN, 2004f) – a percentage that would be the highest annual increase from 1990 through 2002. Transplant programs were opening where none had existed previously, and existing programs were seeking to expand their capabilities. A solid organ transplant program was a badge of honor for a hospital or academic medical center, and it often generated publicity for the institution as well.

The race to develop the next major immunosuppressant drug was well underway, led by Dr. Tom Starzl. Dr. Starzl first reported the use of a Japanese compound called FR900506 in 1987, when he used it to suppress the immune system in rats given heart transplants. (Lee, 1987) By the early 1990s, studies conducted at the University of Pittsburgh were showing that the drug, now called FK506, was a much more potent suppressor of the immune response than cyclosporine. (Demetris, 1991)

There were still many questions to be answered about the new drug, also known by the generic name of tacrolimus. It was so strong that most transplant recipients taking it were able to reduce the use of steroids to supplement their anti-rejection pharmacotherapy regimen. This spared transplant recipients from many of the unwanted side effects of high-dose steroid use, particularly the facial puffiness that made some recipients almost unrecognizable. There was concern about the possible neurotoxic effects, as these were not observed as frequently with cyclosporine. (Klintmalm, 1996) FK506 was also proven useful in what was termed "rescue" immunosuppression – when a transplant recipient was rejecting their new organ on existing drugs, the patient could possibly be switched to FK506. (Armitage, 1991)

With a strong data set from studies conducted around the world, the US FDA approved the drug, now called Prograf, for marketing in April 1994. The number of primary immunosuppressants available had doubled overnight. Though the drug was approved initially for use only in liver transplant recipients, it was prescribed clinically for other types of transplants in what is known as "off-label" use and eventually gained FDA approval for use in kidney transplants.

As the number of transplant centers and anti-rejection drugs increased, also on the rise was the number of diseases for which organ transplantation was considered a therapeutic option. Refinement of surgical techniques and improved immunosuppressive regimens offered many patients a second chance. The number of lung transplants performed in the US increased by 400% during the 1990s, saving the lives of people with cystic fibrosis, emphysema, chronic sarcoidosis, or idiopathic pulmonary fibrosis. The number of pancreas transplants also increased by 400% during the same period, providing treatment for patients with diabetes and other pancreatic diseases. Small intestine transplants showed nearly a 1400% increase in the 1990s on a limited number of patients. (OPTN, 2004g) These patients are unable to gain nutrition through the normal digestive system for a variety of reasons and must be fed through a process called TPN (total parenteral nutrition) where nutrients are administered through a tube or catheter connected to a major vein in the patient's chest cavity. When TPN is no longer effective, a small intestine (small bowel) transplant can restore their ability to process the nutrition needed to survive. (Asfar, 1996)

The number of liver transplants nearly doubled in the 1990s as did the number of simultaneous kidney/pancreas transplants. Heart transplants and heart/lung transplants remained essentially at the same level during the decade, and kidney transplants increased by 35%. (OPTN, 2004h)

While the operating rooms were busy, the number of people registering to be placed in line for an organ transplant was growing rapidly. In the period from 1992-1996, the waiting list grew by an average of nearly 14% per year, adding over 20,000 Americans to the list. (OPTN, 2004i) People waiting for kidney, liver, and lung transplants saw their waiting times increase significantly, with the irony being that by the time a patient was sick enough to make it to the top of the transplant list, their illnesses made the transplant ineffective in many cases.

Living donation was a valid therapeutic option only for those in a need of a kidney transplant during most of the decade, as living split-liver and split-lung transplants were still considered experimental, and living donation was not an option for those needing a heart, pancreas, or small bowel transplant. As the shortage of donor organs evolved into a public health crisis, many individuals, groups, companies, and government agencies realized that something had to be done to try to improve the situation for those awaiting a life-saving solid organ transplant. The prevailing belief seemed to be that if more people knew about the success of organ transplantation and the relative ease of becoming an organ donor after death, that organ donation would increase, creating a positive outcome for all aspects of transplantation.

Early Efforts to Increase Organ Donation

The earliest efforts to increase organ donation were often expedited by individual seeking a donor organ for a family member. The most common example of this was a parent obtaining local media coverage to publicize the plight of their child who was desperately in need of a life-saving organ transplant. In the 1980s, when organ transplantation surgeries could still make local news, these types of stories had the potential to benefit all parties involved – the news story might encourage someone to donate the needed organ and the station could claim to have helped save the child's life.

In the fall of 1983, two year-old Trine Engebretsen's diseased liver was failing quickly. After countless tests, her doctors had bad news for her parents – without a liver transplant, she was sure to die, and probably in a short period of time. To complicate the situation, a liver transplant in a patient that young was considered experimental and would not be covered by insurance. The possibility of finding a suitable donor was also reduced because a donor liver would have to be small enough to fit in her small body – meaning that the donor would have to also be an infant or toddler.

While Trine battled through her illness for weeks, her mother used Trine's dual citizenship (US and Norway) to secure funding for her medical expenses from the Norwegian government. With the financial situation stabilized, Mary Ann Lunde, Trine's mother, started a massive publicity campaign to spread the story of her daughter. Among those assisting her were celebrities, sports and political figures. Mary Ann secured appearances on networks news programs, morning shows, and talk shows, and she also testified in Congressional hearings regarding organ donation.

Time was clearly running out for Trine, but at the last possible moment, a suitable donor liver was secured. The surgery took place in Pittsburgh, and after 18 hours in the operating room, Trine was on her way to a complete recovery. (Alpha-1 Foundation, 2003) There is no way to know if Mary Ann Lunde's media campaign helped secure the organ donation that saved her daughter's life, but today, mother and daughter remain heavily involved in promoting organ donation. The author has interviewed mother and daughter several times over the past 15 years and produced several video programs on organ transplantation featuring their story. In an unusual medical twist, Trine's body has accepted the donated liver to the extent that she no longer requires anti-rejection medications. (Town Crier, 2001)

Celebrity Involvement

In our celebrity-driven world, the involvement of major celebrities with a charitable cause can potentially make a significant impact. In 1989, Wendy Marx, a recent college graduate, was stricken with a severe case of Hepatitis B that quickly shut down her liver and put her into a coma. With time running out, a well-known sports figure stepped in quickly to assist. Olympic gold medalist Carl Lewis was collaborating on his autobiography with Wendy's brother Jeffrey Marx. Carl Lewis flew immediately to San Francisco, holding an ad hoc press conference to explain Wendy's story and ask the public to increase organ donation so that Wendy and others might have a chance to live.

Once again, though there is no conclusive methodology to link Carl Lewis' effort to a specific organ donation, a suitable liver was donated, and Wendy Marx had a second chance at life.

Shortly after her recovery, Wendy took the path chosen by many transplant recipients – to try to give something back to the cause of organ donor awareness. With the help of Carl Lewis, the Wendy Marx Foundation for Organ Donor Awareness was formed in 1990. The efforts of the foundation include:

- The Wendy Marx Foundation helped start a transplant fellowship for doctors
- Wendy and Carl were co-chairs of the first U.S. Transplant Games.
- The Wendy Marx Foundation formed the U.S. Sports Council on Organ Donation, a group of high-profile athletes, coaches and journalists
- The Wendy Marx Foundation's educational video featuring Wendy and Carl, called "Talk, Talk, Talk," has been widely distributed to schools throughout the country
- Leaders of the Wendy Marx Foundation have testified on organ donation before a U.S. Senate hearing and a separate hearing conducted by the U.S. Department of Health and Human Services
- The Wendy Marx Foundation has distributed more than half a million Carl Lewis organ donor cards (designed like sports trading cards but also carrying a commitment to donation)
- Working with other transplant-related groups, corporations, hospitals, churches and schools, the Wendy Marx Foundation has conducted a variety of local and regional awareness programs in some 20 states (Wendy Marx Fdn., 2003)

Wendy required a second transplant and was waiting for a third liver transplant when she died on October 28, 2003. (McLellan, 2003) Her life was extended by 14 years through the generosity of people she never knew, and her efforts to help others in her situation were respected and recognized nationally. The author interviewed Wendy and Carl Lewis several times, most recently in 1999 when they hosted a party in Washington, DC to celebrate the 10th anniversary of Wendy's first liver transplant. Always optimistic in spite of even the most difficult circumstances, the transplant community mourned her passing while remembering her as a truly inspirational champion for the cause of increasing organ donation.

Cause-related Marketing

The largest cause-related marketing event in organ transplantation is the US Transplant Games, first held in Indianapolis, Indiana in October 1990, and sponsored by Sandoz (now Novartis) Pharmaceuticals. As the company that discovered and developed cyclosporine – the most widely used anti-rejection drug at the time – Sandoz believed that the event would serve to increase organ donor awareness, reinforce the idea that solid organ transplantation was viable clinical therapy for a wide range of life-threatening diseases, and offer a means of improving the company's image among their key customers – transplant recipients who took the medication and the physicians who prescribed it. The public relations material for the event noted that "as much as the Games is an athletic event that calls attention to the success of organ and tissue transplantation, it is also a celebration of life among the recipients, their families, and friends." (NKF, 1990)

There were about 400 recipients of heart, kidney, liver, lung, and pancreas transplant who participated in the 1990 US Transplant Games. Media coverage of this unique event was substantial, though not all was positive. Some questioned the wisdom of having heart or lung transplant recipients competing in events such as running races. Those voices were few, and easily overcome by the fact that transplant recipients must maintain a healthy lifestyle that includes exercise to help maintain their transplant.

Mirroring the growth of organ transplantation during the 1990s, the US Transplant Games became the showcase, all-encompassing event for the transplant community during the decade. Medical conferences on transplantation were scheduled in the same time and location of the Games so that doctors and nurses could cheer on their patients. Companies offering a wide range of products and services to transplant recipients set up exhibit space around the sports venues the same way Pepsi and Nike might at the Olympics. Every constituency within what is commonly referred to as "the transplant community" has a representative presence at this event.

The US Transplant Games experienced a dramatic growth rate in participation during the 1990s. From 400 in 1990, the event expanded to over 800 in 1992, when the US Transplant Games was held in Los Angeles. The combination of the emotional and uplifting stories of the transplant athletes (as they were now called) and convenient access to celebrities provided another powerful boost to the event. Where media coverage was limited in 1990 by the minor market status of Indianapolis, there was no such problem in Los Angeles. 15 camera crews from US and Canadian TV stations covered the opening ceremonies at the UCLA track stadium, and the event received another boost for the next time around. 1994 saw about 1200 participants in Atlanta, followed by 1600 in Salt Lake City in 1996, and a similar number in Columbus, Ohio in 1998.

The US Transplant Games has garnered millions of media impressions over the past decade, with some stations covering their local teams of transplant recipients in the same fashion that US media covers results of American Olympic athletes. The stories about the event almost always reference the critical need for organ donors, and in some anecdotal cases, transplant recipients have been told that their donor's family saw something about the Transplant Games that motivated them to donate the organ of their loved one.

The 2004 US Transplant Games will be held in Minneapolis, Minnesota, with nearly 2000 transplant recipients competing in 13 sports, celebrating their second chances at life, and thanking the donor families and living donors who make it all possible.

Impact of growth of transplant waiting list

As the US organ transplant waiting list grew rapidly in the 1990s, the multiple effects of that growth were felt by people in many ways, none of them positive. The first and most devastating effect was the increase in the number of people who died while waiting for a transplant. Between 1995 and 1999, the number of people who died every day in the US waiting for a transplant nearly doubled, from 10 per day in 1995 to 19 per day in 1999. (OPTN, 2004j) While they waited, these patients also were getting sicker. This problem was particularly difficult for patients in need of a liver transplant, in that there is little available medically to sustain liver function for those with serious liver failure other than a transplant. Artificial liver devices have been used in limited trials (Rossi, 2003) but are not widely available. Kidney patients can spend more time on dialysis, heart patients can benefit from drug therapy or mechanical heart devices, and parenteral nutrition can sustain those in need of a small bowel transplant. The liver transplant situation in the US has been the subject of heated debates within the transplant community, the federal government, and hospitals that perform large numbers of liver transplants.

The divergent and passionate arguments on both sides came to a head in 1996, when the US Dept. of Health and Human Services, led at the time by Sec. Donna Shalala, called for open hearings on organ allocation policies. Though liver transplants were not mentioned specifically in the request, the nature of liver transplantation brought much of the focus of these hearings to liver allocation. The hearings were seen by many as a "trial" for UNOS, the sole government contractor for management of organ allocation.

Liver transplant centers such as the University of Pittsburgh that complete a large number of liver transplants showed research illustrating the fact that the graft (organ) survival and patient survival times were longer in correlation with the number of liver transplants the center performed. People come to Pittsburgh from all over the US for liver transplants, and that includes some of the most difficult cases that less experienced transplant programs cannot handle. Under the "sickest first" concept, generally the most critically ill patients would be found at a high volume center like Pittsburgh, meaning that waiting times would be shorter as critically ill patients moved to the top of the list. John Fung, MD criticized the UNOS regionalization of liver allocation, noting that seriously ill patients were dying while livers that would have saved their lives were retained regionally for elective liver transplants for those in an earlier stage of liver disease. (Kolata, 1996) The author attended these hearings in their entirety. In one emotional piece of testimony, a woman whose fiancée died waiting at Pittsburgh stated that a California man was "beeped off the golf course" to receive a liver transplant locally while her fiancée lay comatose in an intensive care unit.

The other side of the argument, represented by smaller transplant centers and UNOS, was that the financial gain and prestige offered by a large liver transplant program was motivating the desired changes, and that poor and minority communities would be deprived of an important medical service if the government forced lower volume liver transplant centers to close.

Dr. Anthony D'Alessandro, a transplant surgeon at the University of Wisconsin, said, "We are here because of a very vocal minority of transplant centers who are well connected." They hope, he said, that the rules can be made to "allow them to flourish as they once did." (Kolata, 1996)

Elected officials were involved as well, with somewhat suspect motives. An investigation of UNOS by Forbes in 1996 asked:

> Why not simply bring in another contractor to ration organs? Good luck. The congressional committee in charge of such matters is headed by Representative Thomas Bliley, from UNOS' home city of Richmond. His cousin Paul S. Bliley is a law partner of UNOS lawyer Malcolm E. (Dick) Ritsch. Last fall, then-Louisiana Congressman Robert Livingston, whose home state includes eight profitable transplant centers, pushed through a bill halting further attempts by Shalala to control the contractor. (McMenamin, 1996)

In March 1998, Sec. Shalala announced a new federal regulation, known as the "final rule" that called for organ allocation based on medical criteria, not geography. (US Dept. of HHS, 1998)

The response of many within the transplant community was swift, and in many cases, harsh. There claims that the rule was tantamount to the federal government getting involved in the decisions over which patient would get the next available liver. There were competing studies, all thoroughly researched and critiqued, touted throughout the media in the general public as well as within the field of transplantation. The outcry was powerful enough Congress brought in the Institute of Medicine, an independent research entity that is part of the National Academies of Science, to conduct a detailed study of all aspects of the issue and deliver a report that would be considered in formulating the language of regulation or legislation regarding the US transplant system.

While the press releases flew, and the lobbying intensified, the IoM took about 9 months to complete the study, and when the results were announced in July 1999, both sides claimed victory. The political and legal wrangling continued, with questions about the constitutionality of a regulation that would strengthen the role of a private entity – UNOS – in supervising the allocation of organs in the US. On April 4, 2000, the US House of Representatives passed HR 2418, a bill that was designed to nullify Sec. Shalala's final rule. The legislation moved on to the US Senate, where it stalled in a committee and never passed.

Regional differences in organ availability

A major discussion point during the heated debate regarding organ allocation was the fact that there are significant differences in deceased donor organ donation rates in different parts of the country. Based on a per-capita analysis of consent rates, there was a concern about a negative impact on people's willingness to donate their organs or those of a loved one if the organs were rarely used locally. The Institute of Medicine report made this a non-issue, noting that:

> …local preference seems not to be a significant factor in the decision to donate. The committee found little or no evidence to support the assertion that people would decline to donate, or that health professionals engaged in organ procurement would be less diligent in their efforts, if they knew a donated organ would be used outside the donor's immediate geographic area. (IoM, 1999)

The concept that the next available organ would go to the sickest person nationally was also questioned vigorously. Lower volume transplant centers that did not usually take the most difficult cases (sickest patients) were concerned that their transplant numbers would be reduced. "Organs fly, patients die" was the rallying cry of these advocates for maintaining the availability of transplant services in smaller geographic areas, which often contained a high percentage of minority patients. This was one of the primary message points addressed in the Institute of Medicine report. The IoM stated that:

> The evidence is inconclusive that the Final Rule would result in the closure of smaller transplant centers located in areas that are more accessible to the residences of prospective transplant patients. Moreover, even if this were a result of the Final Rule, there is no evidence demonstrating that this would have an adverse impact on the access of minority and low-income patients to organ transplants. (IoM, 1999)

Waiting Times

The use of waiting times on the transplant list is common in attempting to assess the success or failure of the organ transplant system, but the reality is that waiting times are overweighted as a criteria for that type of analysis. Similarly, the use of waiting times as part of a formula to determine who gets the next suitable liver was also determined to be a flawed methodology. People who need a liver transplant were categorized at the time as Status 1 (sickest), Status 2A, 2B, and Status 3. A Status 3 patient would be one that was diagnosed with a liver disease that may require a transplant in the future, but was not in immediate danger. The Status 3 patients would wait years on the list, and though their disease may not have progressed, the combination of geographic proximity and a long stay on the waiting list was helping get liver transplants that were essentially elective at the time of transplant. The IoM had harsh words for those who believed that waiting time was a useful measurement:

> Overall median waiting time, which has dominated the policy debate, is a poor measure of differences in access to transplantation. Status specific rates of pretransplantation mortality and transplantation are more meaningful indicators of equitable access. (IoM, 1999)

The IoM recommendation on this topic left no doubt about the opinions of the panel:

> The heterogeneity and wide range of severity of illness in statuses 2B and 3 make waiting time relatively misleading within these categories. For this reason, waiting time should be discontinued as an allocation criterion for status 2B and 3 patients. (IoM, 1999)

After additional research and debate within the transplant community, a new system for categorizing medical urgency for those in need of liver transplant went into effect in February 2002. The system is known by the acronym MELD (Model for End-stage Liver Disease) and PELD (Pediatric End-stage Liver Disease). Only Status 1 – patients who would die within 7 days without a liver transplant – remains in the new system. All other patients are rated according to a point scale from 6 (least ill) to 40 (gravely ill). The points are calculated using a mathematical formula that uses the diagnostic scores on a series of objective medical tests that rate liver function. The benefits of this system include the removal of subjective physician analysis as a factor in determining the listing status of their own patients, and reducing the use of waiting time as a factor to a means of breaking ties between patients with the same MELD score and blood type in the same geographic sharing area.

In the two years that have elapsed since the MELD/PELD system was put into practice, most people involved in liver transplantation seem to appreciate the improvement. An analysis after 6 months on the new system showed a 23% reduction in the number of patients who died while waiting for a liver transplant or had to be taken off the list because they were too ill to undergo the procedure. (UNOS, 2002) The MELD/PELD process is an excellent example of what can happen when groups with divergent opinions about an issue in transplantation work together toward the goal of improving patient outcomes.

The Role of UNOS

The United Network for Organ Sharing celebrated its 20th Anniversary on April 5, 2004. The organization has been part of the tremendous growth of solid organ transplantation in the US, and national organ networks in other countries have adopted many of its processes and techniques. However, as the only group to ever hold the government contract to manage the nation's organ procurement and allocation system, UNOS has some detractors. Most businesses that are government contractors face competitive bidding and diligent oversight by their customers. There are people in the federal government, sectors of the transplant community, and public policy analysts who believe that the United Network for Organ Sharing has evolved into a close-knit group that sometimes puts the interests of a select portion of its membership, political allies, and itself above the best interests of critically ill patients. Among the criticisms during the past decade, financial management and anti-competition maneuvers sparked negative publicity for an organization whose primary mission is to help save lives. The 1996 Forbes review of UNOS offered several examples:

> Craig Howe, executive director of the National Marrow Donor Program, recently expressed interest in having his organization bid on the organ contract. After UNOS found out he was interested, his board members, who include 14 physicians, axed him. Although some powerful and prominent surgeons like {John} Fung are an exception, most doctors involved in the business fear offending UNOS lest their organ supply be affected. (McMenamin, 1996)

With regard to the government contract to manage the US transplant system, Forbes noted that:

> Realizing that UNOS is out of control, {Donna} Shalala has put out feelers for a replacement. "I hope we have some bidders this time," sighs Claude Fox, a pediatrician who, as administrator of the Health Resources & Services Administration, oversees transplants for Shalala. The only prospect so far is Santa Monica-based Rand. Determined to see that Rand does not walk off with the contract, UNOS' lobbyists are pushing for a law that would insure that {Walter} Graham's group will keep the contract forever. Last month {Rep. Thomas} Bliley's committee held hearings on a bill which would require the organ rationing contractor to have experience, something no group but UNOS has. It would also allow UNOS' members to vote on the choice. (McMenamin, 1996)

Despite the critics, UNOS continues to thrive and has retained the contract to run the OPTN since 1984.

Review of national public awareness campaigns to increase organ donation

As the US transplant waiting list and the number of patients who die while waiting for a transplant have increased dramatically over the past decade, public awareness campaigns designed to increase organ donation have become an integral part of the problem-solving plans. The basic premise is very simple – if people found out how easy it was to become an organ donor, and how much it could help others, organ donation would increase. The reality, however, is rooted in statistics that belie that concept. As noted earlier, 81% of Americans support organ donation (Pew, 1999) but only half of those asked to consent to organ donation say yes. (Siminoff, 2001) Given the potential of recovering 6-7 usable solid organs from each possible donor, that 30% gap, if closed, could provide thousands of life-saving organs to critically ill patients.

Another important aspect of the discussion is centered on those that are never asked for consent. It is generally held that when looking at the entire population of possible deceased donors, the families of 1/3 of this group say yes, 1/3 say no, and 1/3 are never asked. Though the optimal goal of requesting donation from every potential donor family is unachievable, it's clear that the "never asked" population can also provide a significant improvement to the donor shortage. In 2002, there were just over 6,000 deceased organ donors, meaning that there were probably about 6,000 potential donors whose families were never approached about donation. If they all were asked, about half of them (3,000) would have agreed to donation, providing thousands more organs for patients across the country.

The delineation of support for organ donation must also factor in the potential differences between an individual's self-proclaimed support for organ donation as evidenced by signing a donor card and that same individual agreeing to donate the organs of a loved one at the moment of their untimely death. The transplant community, the federal government, and the many public and private entities with a stake in organ transplantation have placed a tremendous bet on the concept that increased awareness of the need will lead to increased donation in both circumstances.

The Coalition on D

Acid Free
Start - pg. 41

Founded by UNOS lition on Donation is
comprised of many vard the same goal: "to
educate the public onceptions about
donation and crea 003) The Coalition on
Donation is a no hrough donations from
corporate spons

The Coalition on Donation provides educational products and services, public awareness materials, donor cards, article templates, branded clothing such as hats and shirts, and electronic materials such as digital presentations about transplantation. Local chapters of the group operate in 49 states and the District of Columbia, sponsoring events to promote donor awareness and collaborating with the national group on projects such as the annual National Donor Sabbath.

The Coalition on Donation also produces television PSAs that are broadcast through donated airtime in the hopes of increasing awareness of the need for more organ donors. Over the years, these spots have featured recipients, donor family members, and people awaiting a transplant. In 2000, Connie Payton, widow of football legend Walter Payton appeared in one of the PSAs. Walter Payton died of liver disease before receiving a liver transplant, though it appeared he would not have been eligible to receive a transplant since he had also developed cancer of the bile duct. (AP, 1999)

The Coalition also disseminates information to combat the myths surrounding organ donation and transplantation that may discourage people from consenting to organ donation. The most common of these misconceptions is that medical professionals will not work as hard to save the life of a patient who is an organ donor. Despite all these efforts in public education, utilizing a national network of chapters, the latest technologies in distribution, and millions of dollars in donations, the waiting lists for transplants increase. The Coalition on Donation offers high quality material and well-designed program content, yet the impact of their services seems to be limited in light of the magnitude of the problem. However, the Coalition on Donation is not alone in this regard.

Mickey Mantle Foundation

Mickey Mantle was by many accounts the greatest baseball player ever – a unique combination of speed, power, and ability to perform under pressure. In 1995, when he was critically ill with liver disease brought about by alcohol abuse, he was added to the transplant list at Baylor Medical Center in Dallas and told to expect a several month wait. To the surprise of many, and the dismay of some, his wait lasted less than two days. News coverage of Mickey Mantle's liver transplant and post-operative complications was at saturation levels nationally, and particularly intense in Dallas, where the surgery was taking place, and in New York, where Mantle was a hero athlete to millions of adoring fans. Though nobody had ill wishes toward Mantle, there was an extreme level of scrutiny applied to the allocation process that found him an organ in under 48 hours.

In a review of the crisis communications efforts of the hospital's public relations staff during the Mantle hospitalization, lead PR executive Jennifer Coleman noted that:

> On Thursday, June 8th, at 4:30 a.m., Mantle went into surgery. News coverage began at dawn with the network morning programs. "We had doctors ready at 5:30 a.m. to accommodate Good Morning America and Today. We had all the sports stations and CNN, too," she adds. News conferences were held that day and the next at 9 a.m. and 1 p.m. At 9 a.m., the reporters needed something from overnight. The afternoon time was picked because of the doctors' schedule, and it seemed to work for both coasts. Coleman says competition was so intense among local TV stations that someone called the hospital switchboard and offered an operator $20 to "lose" the phone messages from the competing stations. (Medical News, 1995)

Mickey Mantle only survived 2 months with his new liver, as he also had cancer. There were concerns that his cancer should have precluded him from being listed for a transplant, but the surgical team said that the extent of the cancer was not discovered until the liver transplant surgery was in progress. Shortly after the transplant, Mickey Mantle, like many transplant recipients, expressed a desire to give something back to the transplant community. The Mickey Mantle Foundation was created while he was still alive and formally launched just days after his death. Capitalizing on the popularity of baseball memorabilia, the idea for a Mickey Mantle Organ Donor Card was the cornerstone piece of the Foundation's awareness campaign. The card included a direct message from Mantle:

> "Don't drink or do drugs. Your health is the main thing you've got, so don't blow it. Second, think hard about being an organ donor if the time ever comes. Sign this card, carry it with you and let your family know how you feel." (Mantle, 1995)

Hundreds of thousands of the Mickey Mantle organ donor cards have been distributed since 1995. Hundreds of millions of people heard about Mickey's organ transplant, and many of the news stories mentioned the shortage of donor organs. In 1996, the first full year after Mantle's death, the number of deceased organ donors in the US increased 1%. (OPTN, 2004k)

Michael Jordan Campaign

After winning 6 NBA titles, an NCAA title, and an Olympic gold medal, Michael Jordan is considered to be the greatest basketball player in history and one of the most widely recognized athletes in the world. In 1996, through contacts at the Regional Organ Bank of Illinois, Michael Jordan agreed to lend his name and face to the cause of increasing organ donor awareness. The Coalition on Donation was responsible for the national rollout of this campaign, that included posters, organ donor cards, and a television PSA with Michael Jordan delivering the tagline "Share your life, share your decision." The campaign was announced at Michael Jordan's Steakhouse in Chicago, at a well-attended press conference. The author attended this event and videotaped the proceedings. Michael Jordan, however, did not attend the event, causing some in the transplant community to question his true commitment to the effort. Those concerns were addressed by the fact that Jordan usually received millions of dollars for attaching his name to any product or service, and that the publicity for organ donation generated by his participation was not affected by his absence at the event.

Large color posters featuring a smiling Michael Jordan and a brief message about organ donation were widely distributed by the Coalition on Donation and many of their local chapters. A companion donor card with the same image as the poster was also produced and distributed at many sporting events. Some people stole the posters, thinking they might have future value as sports memorabilia.

The campaign featuring Michael Jordan was critical as it was seen to help address the concerns in the minority community about the fairness of the organ allocation system, and reinforce the need for minority donors who could potentially provide better matched organs to minority patients awaiting a transplant. In the Philadelphia area, 75% of white respondents to a survey regarding organ donation said they would be likely to donate, but only 53% of African-Americans said they would donate. (Hollreiser, 1996)

Kevin Sparkman, Community Relations Manager for the local OPO noted at the time:

> Organ donation organizations say awareness and education greatly increases the likelihood of donating. That is why the Michael Jordan campaign can be so effective, particularly in black communities, Sparkman said. "Michael Jordan is not going to be the magic bullet," Sparkman concedes. "But it is amazing when you go to health fairs with [Jordan] posters and brochures and see how quickly people snatch it up. They don't care what it's about. They see his face and snatch it up." (Hollreiser, 1996)

The perceived impact of the Michael Jordan PSA was strong enough that some OPOs actually purchased advertising time so that the would run during peak viewing times, instead of relying on donated time that is primarily available during the least-watched times of day.

The results of the campaign were perceived as positive but it is impossible to prove a direct link between this campaign and increased donation. There are numerous anecdotal reports and claims to this effect, including an undocumented claim on the website of the PR agency that developed the campaign:

> On behalf of our clients, we have successfully: Created and now manage an ongoing national advertising and public affairs campaign featuring Michael Jordan to educate Americans about organ donation and the need for transplant organs. The program has resulted in an increase in the number of donors nationwide. (Summit Group, 1999)

Once again, a significant amount of time, expertise and money spent, with a true A-list celebrity as a spokesperson for the cause, a national campaign with print and broadcast media, and only a tiny increase (1.1%) in the number of deceased donors recovered in the first full year of the campaign. (OPTN, 2004l) This campaign was run in addition to the many local and regional donor awareness campaigns executed during 1997.

National Donor Sabbath

To promote organ donation and reinforce the fact that most major religions observed in the US accept organ donation as a reasonable practice, the Division of Transplantation within the US Department of Health and Human Services sponsors the National Donor Sabbath. The event takes place over a Friday-Sunday timetable to cover the Sabbath observances of Christian, Jewish, and Muslim faiths. The government essentially asks clergy in all religions to discuss the importance of organ donation with their congregations in a variety of ways – in their sermons, by hosting recipients of life-saving transplants in celebratory services, by promoting discussion of organ donation among family members, and by bringing in guest speakers from the transplant community to discuss the shortage of organ donors and the impact of the shortage. The National Donor Sabbath has been an annual event in the US since 1996.

Since surveys have shown that over 40% of people in the US attend a religious service every week, (Inglehart, 1997) a huge audience for the donor awareness message is available and presumably paying attention. Local organizers of the event even provide a list of biblical references to organ and tissue donation that can serve as starting points for the discussion. Some examples:

Genesis 2:20-30 Bone transplant: A rib taken from Adam to give life to Eve
Leviticus 1:7 "Thou shalt love thy neighbor as thyself."
Deuteronomy 30:15-20 "Choose life so that you and your descendants may live"
Luke 4:16-21 "...recovery of sight to the blind."
Revelation 21: 4-5 "In eternity we will not need our earthly bodies: Former things will pass away, all things will be made new." (Mid-West Eye Banks, 2000)

With about 250 million people in the US, that 40% figure attending services translates into 100 million people who might hear a message about organ donation if every possible congregation was involved. If only 2% of clergy in the US agreed to participate, that audience would be reduced to 2 million. So using 2001 as a sample year, when the National Donor Sabbath was well-established in its sixth year, if 2 million people heard a message about the importance of organ donation from a source they trusted, and 80% of the public supports organ donation, why were there only 107 more deceased donors in 2002 than in 2001? (OPTN, 2004m) The answer is that communications about organ donation appear to be an adjuvant therapy for the donor organ shortage in the US – despite the biggest names, the best planning, huge audiences and numbers of impressions, the deceased donor numbers have now been outpaced by living donors. There are now more people willing to have a perfectly healthy organ extracted from their body while they are alive than those whose families agree to have them removed after their death.

Increasing donation – current efforts

Increasing public awareness is one of many methodologies used in an attempt to increase organ donation. There are a number of other efforts in various stages of acceptance that may increase donation, though there are complicating factors associated with each one.

Financial Incentives

The National Organ Transplant Act makes it illegal to sell or trade in human organs in the United States. While there are many valid reasons for this regulation, the severe shortage of donor organs in the US has brought about the limited consideration of financially incentivizing those who are presented with the decision to donate the organs of a loved one. As with most issues in organ transplantation, there are strong opinions on both sides of the issue, and a number of ethical factors to analyze as well.

The nation's first initiative to provide financial incentives to increase organ donation started in Pennsylvania, with the passage of PA Act 102 in 1994. Among the stipulations in this bill was the establishment of a statewide organ donation "trust fund" which residents of the state could contribute to by checking off a box on their state income tax return. The money from this fund would be used to support educational initiatives as well as provide a financial incentive for families of potential organ donors. The initial idea was to provide up to $3,000 toward funeral expenses for a deceased organ donor. To avoid the conflict with federal law regarding payment for organs, the money would be paid directly to the funeral home. This figure was eventually reduced to just $300, as the implementation of this specific portion of the legislation dragged on through the years with various committees, state commissioners, and governors exerting their perspectives as well. Another change was that the $300 could be used to pay for lodging and incidental expenses incurred by the family of the organ donor, or a living donor (an addition due to the increase in living donation). After 8 years of effort, the program started in the spring of 2002. (Wiggins, 2002)

The federal government was paying attention to the rates of organ donation in Pennsylvania. With strong support from elected officials and an innovative OPO driving the effort, the state has had a 75% increase in organ donation since the law was enacted – an astonishing achievement considering the national trends during the same time period. (Green, 2002)

In June 2003, the US House of Representatives held committee hearings on authorizing the Secretary of Health and Human Services to fund demonstration projects to study the potential impact of financial incentives on the rates of organ donation in the US. Heated comments on both sides of this issue included:

> I believe in financial incentives, that could for instance place Federal dollars into the estate of a donor, would probably serve as an incentive to get--we know that many Americans voluntarily check off the form when we renew our driver's license or in some other way we fill out an organ donor card. But many Americans, most Americans I believe, don't do that...and to me, saving an additional life or thousands of

> lives certainly overcomes any ethical argument that I can see for creating a financial incentive. (Greenwood, 2003)

> It has been against the public policy of this country to pay people for organ donations for many, many years, and the reason is because legislative bodies have felt that it was repugnant to give financial incentives to folks to donate their own organs, and the feeling is that it would unduly put pressure on low-income individuals to do that. I see no need to move away from that public policy. (DeGette, 2003)

The following month, Rep. Greenwood introduced HR 2856, a bill that would formally authorize up to $25 million per year over the next several years to fund these demonstration projects, including reimbursement of incidental expenses for living donors, and a payment to the estate of deceased donors. In November, 2003, Sen. William Frist (R-TN), a thoracic transplant surgeon, was instrumental in passing S 573, known as the Organ Donation and Recovery Improvement Act. This bill, which was signed by President George W. Bush on April 5, 2004, picks up one key portion of HR 2856, the reimbursement of incidental expenses for living donors. A sum of $5 million is set aside in the bill for this purpose. The bill does not contain any initiatives relating to payment for deceased organ donation. (US Senate, 2003)

Presumed Consent

Another ethical dilemma related to organ donation is the concept of presumed consent. This is essentially the exact opposite of the current system of obtaining deceased organ donation in the US. Instead of approaching the next of kin of the deceased for permission to recover their organs for transplant, under presumed consent, everyone is a donor unless they have signed a card stating that they do not want to be an organ donor, and the next of kin are not involved in the process. According to the Presumed Consent Foundation, the system would operate as follows:

> An individual who does not want to be an Organ Donor would have to "opt-out" by entering their name on a National Registry maintained by OPTN - the same organization that now keeps the National Waiting List of transplant candidates. When a person died under circumstances that would permit Organ Donation, a search would be made of the Registry. If their name did not appear in the Registry, it would be presumed they had consented to be a Donor. While the family would be advised of this information, their consent would not be required, and no one would be allowed to override the donation. (Presumed Consent Foundation, 2003)

There are a number of countries in Europe that have implemented presumed consent successfully. Spain currently has the world's highest per-capita rate of deceased donors, with a rate almost 50% higher than the US. (Kerbaj, 2004)

Those types of numbers make the transplant community in the US take notice, but given the extremely litigious society we live in, extreme caution is demanded by all who even dare comment on the topic. The American Medical Association noted in a position statement that:

> A system of presumed consent for organ donation, in which individuals are assumed to consent to be organ donors after death unless they indicate their refusal to consent, raises serious ethical concerns. For presumed consent to be ethically acceptable, effective mechanisms for documenting and honoring refusals to donate must be in place. In addition, when there is no documented refusal by the individual decedent, the family of the decedent would have to be contacted to verify that they do not know of any objections to donation by the decedent while living. (AMA, 2002)

It's important to note differences of opinion between the general public and experts in transplantation on this sensitive subject. A 2002 study of members of a leading transplant organization found that 3 out of 4 supported presumed consent, and nearly 40% said it was the best way to increase organ donation. (Oz, 2002)

Some states are in the process of enacting their own presumed consent laws for citizens of those states. In Texas, a bill put forward in March 2003 declares simply: "A decedent who is 18 years of age or older and dies in this state is presumed to give all or part of the decedent's body to an organization identified in Section 692.005(1)." The term "organization" in this law refers to the appropriate organ procurement organization in Texas. (Homer, 2003) This bill never received a hearing in the Texas legislature, though it did have some public support. (Texas Medical Assoc., 2003)

The idea seemed to be gaining traction in 2003, as supporters were gaining ground in similar efforts in New York, California, and Rhode Island. (Robeznieks, 2003) The potential improvements to donor rates are significant, but the role of the family of the deceased potential donor must be carefully considered as well. No hospital, OPO, or transplant center would want to deal with the unimaginably bad publicity that would be generated the first time there was a discrepancy regarding a patient who, according to the family, had "opted-out" and did not want to be an organ donor, but their organs were taken anyway.

Some states are inching along the continuum towards presumed consent with the premise of "donor rights." This term refers to the fact that an individual over 18 who signs a donor card, enters into a statewide donor registry, or completes a similar affirmation of their wishes to be a donor must have their wishes honored by law as it is their legal right to be a donor. At the time of death, the next of kin is presented with the appropriate documentation and notified of the wishes of the deceased. This approach was controversial when it started in the late 1990s but several states have enacted laws to this effect, or are in the process of doing so.

The reality for advocates of presumed consent in the US is that they will probably never see a Spanish-style presumed consent law passed at the federal level. There are simply too many legal, ethical, and regulatory hurdles for this approach to be enacted nationally. However, pockets of strong support from the transplant community and determined state legislators may see a state law passed implementing presumed consent. The question that will inevitably be raised if this happens is one of constitutionality where the laws of a state conflict with federal laws. While the battle rages on, undoubtedly patients in need of a life-saving organ transplant will die as the legal machinations continue.

Living Organ Donation

For a potential transplant recipient, the benefits of obtaining a transplant from a living donor can be significant. The complete health of the donor can be assessed in a detailed manner, a process that's not possible with a brain-dead or non-heart beating donor. The donated organ or organ portion will be in an ischemic (no blood flow) state for a very short period of time as the donor and recipient will usually be placed in adjacent operating rooms. The less time an organ is without blood flowing through it, the faster it will regain functionality, and that function will probably last longer as well. (Kefalides, 1998)

For many years, living donations of organs came only from relatives of the recipient. The likelihood of a high quality match from a blood relative improved the chances for a positive outcome. Over the past decade, a growing number of living unrelated donors are coming forward to save the lives of spouses, friends, co-workers, teachers, church members, and in some cases, even celebrities or total strangers. With improvements in pre-transplant testing and matching techniques, the results for living-unrelated donors are similar to the living-related donors.

The moral and ethical quandary presented by living-related donation is a significant one. If a family member is critically ill, and unable to wait for a deceased organ donor, that person's relatives may volunteer very quickly to be tested to see if they might be a suitable match – or, maybe nobody in that person's family feels like risking their own life by giving up a kidney to help the "problem" brother. A major component of the pre-transplant evaluation of the living donor is a complete psychiatric workup. It is important that careful steps are taken to insure that the donor was not pressured or coerced into agreeing to donate.

The process of informed consent – having the donor sign a series of documents explaining in detail what is involved in the procedure, the short and long-term risks and recovery process – is the last wall protecting the interests of the donor in these cases. A parent who will gladly offer a kidney to their dying child may not want to hear about the significant risks to their own health, but it is an absolutely necessary part of the living donor process. The author has interviewed a number of living organ donors and their recipients. In one example, an adult child originally refused to let his father donate a kidney to him, fearing for his father's health. He only agreed when his own condition worsened and a less-invasive surgical procedure called laparscopic nephrectomy was developed for removing a kidney from a living donor, reducing the risks for his father. It's easy to see how this situation can have a profound impact on any family.

The pressure to donate may be subtle or quite direct, all affected by the limitless possibilities of family relationships. As originally reluctant family members watch one of their own deteriorate while waiting for a deceased donor organ transplant, the pressure mounts to be tested, or donate if a match is already known. Certainly some people will agree to be tested and probably hope that someone else in the family is a better match. Others may be tested, found to be a good match, but will only agree to donate if the patient is gravely ill. Some physicians may be asked to help a very reluctant donor find a medical "out" so that they would not be subjected to the guilt and anger of other family members regarding their feelings. The fact that better results are obtained when the transplant occurs earlier in the course of disease is just another complicating factor to this sensitive and emotional issue.

The rapid growth of living donation in the US is due to several factors:

- the use of less invasive donor surgery procedures such as laparoscopic kidney removal
- the stagnation of the number of deceased organ donors

- medical evidence reinforcing the benefits of living donor organs over deceased donor organs
- the ability to get a transplant without waiting months or years while the disease worsens

As the transplant community celebrates the 50th anniversary of the first successful human kidney transplant in 2004, living organ donation has taken center stage as a generally safe (for the donor) and highly effective (for the recipient) treatment approach to end-stage renal disease. Living donor split-liver transplantation, where a portion of the donor liver is removed, has also increased in frequency, but with some notable deaths associated with the much more complicated procedure. It would be ideal if there were enough viable organs recovered from deceased donors so that healthy people wouldn't have to donate as many organs, but the UNOS statistics tell us that day is not coming soon, if ever.

Organ Swapping/Directed Donation Registries

The shortage of available deceased donor organs for transplantation has created an environment in which people are developing creative methodologies to combat the problem. The concept of organ swapping primarily involves living donation. A family member of a person in need of a transplant agrees to donate an organ to a person from another family in exchange for a living organ donation from that family to their loved one. The situation evolves when the family members willing to donate are not a suitable match. Mrs. Smith wants to donate a kidney to her son Bill Smith, but does not match. She then agrees to donate a kidney to Mr. Jones' daughter, for whom she is a match.

Then Mr. Jones, or one of the other Jones family members who is a suitable match for Bill Smith donates a kidney to him. While this seems relatively simple on the surface, it exponentially increases the ethical and moral dilemmas associated with living organ donation.

Another approach to this concept was pioneered by the New England Medical Center in Boston under the name Hope Through Sharing. In this program, the living donation of an organ by a family member moves their loved one in need of a transplant to the top of the local waiting list. Launched in 2001, and approved by UNOS as first program of this kind in the US, Hope Through Sharing does have some limitations as patients in medical emergencies and those needing multiple organs remain a higher priority on the waiting list. The swapping of one organ for another heightens the ethical scrutiny associated with transplantation as potentially conflicting with laws against trading anything in exchange for a human organ. The fact that UNOS, the nation's managing organization for the movement of donated organs for transplant, approved this program was used by a newer, more controversial program as a justification for their idea – that a national group could direct the donation of their organs, upon their death, only to other members of the same group. The group is called LifeSharers.

LifeSharers was created by David Undis, a retired insurance broker who studied economics in college. (Sanchez, 2003) Upon enrolling as a LifeSharers member, you receive a specially designed organ donor card to sign that restricts the donation of your organs upon death to other members of LifeSharers. If no LifeSharers member is a suitable match, then the organs can be released to non-members under the standard UNOS guidelines. Undis received enough publicity about his group to quickly draw the wrath of many entities. The American Medical Association, the American Society of Transplantation, and UNOS all slammed the idea. LifeSharers does have some well-respected supporters on the organization's advisory board, including bioethicists, and experts in economics and legal issues. There are no physicians on their advisory board, though some physicians are members of the organization.

The primary issue that critics have with LifeSharers is that it usurps medical necessity as the basis for organ allocation and creates a different class of potential transplant recipients – those who have agreed to become organ donors. According to Dr. Mark D. Fox, chair of the UNOS ethics committee, Lifesharers "bypasses the established allocation algorithm that's based on some objective criteria of medical urgency. It undermines the intent and the clinical basis of the existing system." (Sanchez, 2003)

The response of LifeSharers to all critics is based on the fact that the current system of organ allocation and recovery is clearly failing, resulting in thousands of possibly avoidable deaths each year. LifeSharers believes that true fairness in organ allocation would place those who would give the gift of life at the front of the line to receive it if needed. As noted on the LifeSharers web site:

> As LifeSharers members, you and your loved ones will have access to organs and tissue that otherwise may not be available to you. As the LifeSharers network grows, more and more organs and tissue may become available to you – if you are a member. (LifeSharers, 2003)

David Undis and his LifeSharers members seemingly have a long way to go in their efforts to improve organ availability. As of 11/30/03, there were 1,772 members of the group. One noted bioethicist stated that:

> Mr. Undis's expectations may be unreasonable. Given that the cessation of all brain function without heart, kidney, and liver damage is a rare occurrence, LifeSharers would need at least 17,500 members to achieve a 50% chance that one member per year would become an organ donor. (Rutecki, 2003)

While the scientific innovations of the past 50 years have created a high likelihood of medical success for those who can find a suitable organ in time, concomitant improvements in public attitudes and non-medical processes (such as requesting donation) are needed to maximize the impact of this emotionally charged field of medicine.

Chapter 3 - Research by Survey

We conducted an attitudinal survey including Likert scales on two groups:

Group 1 – general public consisting of randomly selected friends, fellow students, and acquaintances with no regular involvement in organ transplantation, generated through e-mail contacts.

Group 2 – Transplant professionals (physicians, nurses, transplant coordinators, procurement specialists) who spend 100% of their time in organ transplantation. This e-mail list was gathered from subscribers to, and listings in The 2003 International Transplant Directory.

The survey assessed the familiarity with organ donor awareness campaigns and their perceived effectiveness in increasing organ donation, as well as other related questions.

The survey was conducted entirely on-line through the use of a software application called Quask. (www.quask.com) Quask software allows on-line surveying of facts and opinions with a simple interface that helps increase the likelihood that a respondent will complete the survey. Potential survey subjects received an e-mail explaining the project and stating that the answers would be submitted anonymously – an important distinction given the sensitive and personal nature of some of the questions. The e-mail contained an active link that directed the respondent to the electronic survey. Approximately 3000 e-mails were sent out by the author, and 515 responses were submitted.

Attitude Survey on Organ Donation and Transplantation

This survey is being conducted as a component of thesis work toward the completion of a Master of Arts degree in Corporate and Public Communications at Seton Hall University. The purpose of the survey is to assess attitudinal differences on key issues in organ donation and transplantation among the general public and people who work in the field of organ transplantation. The survey will take about 5 minutes to complete.

All responses are anonymous and strictly confidential. If you'd like to receive a copy of the final project, please respond via e-mail. Thanks very much for your participation.

Stuart Katz
katzstua@shu.edu

Group Selection (check one):

- ☐ **I am employed primarily in the field of organ transplantation or related businesses.**
- ☐ **I am NOT employed primarily in the field of organ transplantation or related businesses.**

Please answer the following questions based on your current opinions about organ donation and transplantation. The terms "organ donor" and "organ donation" refer only to donating organs at the time of death unless otherwise noted.

1. From what I've heard, seen, or read the shortage of donor organs is a serious public health problem in the US.

Strongly Agree Agree Neutral Disagree Strongly Disagree

2. I haven't heard, seen, or read much about a shortage of donor organs in the US.

Strongly Agree Agree Neutral Disagree Strongly Disagree

3. Emotional appeals would be effective in encouraging people to donate their organs.

Strongly Agree Agree Neutral Disagree Strongly Disagree

4. Celebrity appeals would be effective in encouraging people to donate their organs.

Strongly Agree Agree Neutral Disagree Strongly Disagree

5. The federal government should play an active role in encouraging organ donation.

Strongly Agree Agree Neutral Disagree Strongly Disagree

6. The perception that wealthy or famous people somehow jump to the top of the transplant waiting list keeps many people from donating organs.

Strongly Agree Agree Neutral Disagree Strongly Disagree

7. I've considered my own wishes regarding organ donation.

Yes No

8. I've discussed my feelings about organ donation with my family.

Yes No

9. I have seen/read/heard advertisements promoting organ donation.

Yes No (skip to #13)

10. Who (if anyone) was featured in the ad(s) you saw, read, or heard?

_______Non-celebrity awaiting a transplant
_______Non-celebrity who had a transplant
_______A celebrity awaiting a transplant
_______A celebrity who had a transplant
_______A celebrity who simply supported the cause
_______Any government official
_______Other (describe)_______________________________

11. The advertisement that I saw/read/heard caused me to consider my own feelings about organ donation.

Strongly Agree Agree Neutral Disagree Strongly Disagree

12. The advertisement that I saw/read/heard made me more likely to become an organ donor.

Strongly Agree Agree Neutral Disagree Strongly Disagree

13. Providing a financial incentive to families such as reimbursing funeral costs would increase the chances of obtaining consent for organ donation at the time of death of their loved one.

Strongly Agree Agree Neutral Disagree Strongly Disagree

14. The federal government's effort to increase organ donation is an example of:

_____a meaningful and beneficial use of tax dollars that will help save many lives
_____a well-intentioned effort that may help somewhat over time
_____another government program that will not improve the situation
_____I don't know enough about this to have formed an opinion

15. (transplant group only) Presumed consent is a good idea that could help reduce transplant waiting lists in the US.

Strongly Agree Agree Neutral Disagree Strongly Disagree

16. (transplant group only) Presumed consent will never be implemented in the US.

Strongly Agree Agree Neutral Disagree Strongly Disagree

17. (non-transplant group only) I know someone who has received an organ transplant.

Yes No

Thank you for your time and assistance.

Chapter 4 - Research Results

In this chapter, each question on the survey will be reviewed with regard to the reasons it was included, and the survey results for each of the two groups included in the survey. While in some cases, the distribution of answers could have been estimated with relative accuracy, there were some surprises. The author believes that the quantity of responses received makes the results relevant despite some limitations. One such limitation was that the need to insure that survey responses were submitted anonymously meant that there was no way to prevent a survey respondent from answering the questions more than once. Collecting the respondent's unique IP (internet protocol) address from their computer through the use of "cookies" was not an option – it would have significantly reduced the response rate if survey subjects knew that their answers could be traced back to them in any way. The author believes that because the survey was explained as a student project, and not for the benefit of any commercial enterprise, that the respondents respected the goal of statistical integrity and only completed the survey one time, though this cannot be documented conclusively.

Two types of statistical analysis were executed on the raw data. For the questions including a Likert scale, a Mann-Whitney U test was used to determine if there was a statistically significant difference in the opinions of the two survey groups. The Mann-Whitney U test is a non-parametric test that is ideal for comparisons of ordinal data in which the relationship between the ordinal rankings cannot be defined conclusively. In this survey, for example, the actual measurement of the psychological distance between "strongly agree" and "agree" compared to the distance between "disagree" and "strongly disagree" can differ for each respondent or each question. Objectively measurable criteria, such as blood pressure, or cholesterol levels between multiple groups can be compared with more powerful parametric tests. The questions in this survey with yes/no answers were first analyzed using the Pearson chi-squared test. When very low numbers in one field of the 2 X 2 table were present, a more stringent analysis called the Fisher's Exact test was run.

Any results that were found to be statistically significant are noted below.

Preface Question – Survey Subjects Primary Grouping

Of the 515 survey responses submitted, 260 (50.5%) identified themselves as being employed full-time in the field of organ transplantation. The sub-groups of people in this category who received the survey invitation electronically included physicians, nurses, organ transplant coordinators, pharmacologists, researchers, physical and occupational therapists, professional and managerial staff at hospitals, organ procurement organizations, and other non-profit organizations with transplantation, and those employed by pharmaceutical companies who develop and market drugs used in the treatment of transplant recipients.

255 (49.5%) of respondents identified themselves as not employed in the field of organ transplantation.

Question 1

1. From what I've heard, seen, or read the shortage of donor organs is a serious public health problem in the US.

Strongly Agree Agree Neutral Disagree Strongly Disagree

The responses to this question were generally as expected. 80% of those employed in the field or transplantation strongly agreed with the statement, and 17% agreed. 1% were neutral, 2% disagreed, and there was not one response that strongly disagreed from this group. Among the general public, 41% strongly agreed and 44% agreed, revealing that the vast majority of respondents in this group recognize the impact of the shortage of donor organs. 13% were neutral, 2% disagreed, and again, not one respondent strongly disagreed with the statement.

The difference in the responses between the two groups was found to be statistically significant, with a P-value of <0.001.

Question 2

2. I haven't heard, seen, or read much about a shortage of donor organs in the US.

Strongly Agree Agree Neutral Disagree Strongly Disagree

This question was designed to look at the quantity of material that the respondents were exposed to regarding the organ donor shortage. Separate from their opinions that were formed on the basis of what they had heard, seen, or read about the seriousness of the issue, this question was strictly quantitative and would address the magnitude of "media impressions" that respondents had received. The question was worded as a negative statement to present a contrast to the previous question and provoke a bit more thought on the part of the respondent. For example, a heart transplant surgeon who knows from her own daily work that there is a serious shortage of donor organs, and read one article about the problem in her local paper can strongly agree with Question 1 (the article explained the problem) and Question 2 (only one article would not qualify as "much").

Here again, there were no big surprises. Among those employed in transplantation. 53% strongly disagreed, and 30% disagreed. Among the transplant community, where medical journals often include articles about methodologies to increase organ donation, there would likely be a vast majority in disagreement with the statement. 6% were neutral, 10% agreed, and 1% strongly agreed. Among the general public, the results should be considered positive for those involved in transplant communications, though there is clearly room for improvement. 18% of the general public group strongly disagreed, and 43% disagreed, meaning that over 60% are stating that they have indeed heard, seen, or read a great deal about the shortage of donor organs in the US. 18% of this group were neutral, 15% agreed, and 6% strongly agreed with the statement – numbers that those in the transplant community would like to reduce significantly.

The difference in the responses between the two groups was found to be statistically significant, with a P-value of <0.001.

Question 3

3. Emotional appeals would be effective in encouraging people to donate their organs.

Strongly Agree Agree Neutral Disagree Strongly Disagree

The techniques used in organ donor awareness campaigns often use emotional appeals. From the parent of a dying child, a sibling, or even an entire family, the encouragement to donate can be dramatic and moving – but would it also be effective? This question was included to evaluate the perceived effectiveness of these types of appeals.

Both groups validate the usefulness of the emotional approach. Among those employed in transplantation, 27% strongly agreed with the statement, and 48% agreed. There were still some skeptics in this group, with 19% neutral, 5% in disagreement, and 0.5% in strong disagreement. The general public rated emotional appeals more effective than those in the field, with 29% who strongly agreed and 55% who agreed with the statement. 8% were neutral to the idea, 6% disagreed, and 2% strongly disagreed. Separating emotion from a life-or-death medical problem is very difficult, and the results seen here, combined with the ease of creating these types of appeals means that emotional appeals will retain their prominence in the toolbox of organ donor awareness campaigns.

Question 4

4. Celebrity appeals would be effective in encouraging people to donate their organs.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Given the growing number of celebrities who have received an organ transplant, it's not surprising that many of them seek to "give something back" by helping promote organ donation. There are also celebrities, such as track star Carl Lewis, who took up the cause when a close friend or relative needs or receives a transplant. The perceived effectiveness of this popular type of approach toward increasing donor awareness was measured with this question.

The results were very similar between the groups. Among those employed in transplantation, 19% strongly agreed with the statement, and 48% agreed, meaning that two-thirds of those respondents in the field believe that the use of celebrities is an effective means of increasing organ donation. 19% of this group was neutral, 12% disagreed, and 1% strongly disagreed with the statement. The general public group had 14% in strong agreement and 49% in agreement – still a solid majority backing the effectiveness of celebrity appeals. 23% were neutral, 10% disagreed, and 3% strongly disagreed with the statement. As of this writing, legendary football announcer Pat Summerall was recovering from a liver transplant. If he recovers successfully, he will likely be the next recognizable celebrity approached to appear in a PSA or print ad about organ donation.

Question 5

5. The federal government should play an active role in encouraging organ donation.

Strongly Agree Agree Neutral Disagree Strongly Disagree

This question addresses the extent to which people in and out of the field believe that encouraging citizens to donate their organs or those of a loved one is an appropriate activity for the federal government.

The survey results show a large difference of opinion between those employed in organ transplantation and the general public. A majority – 51% - of those employed in transplantation strongly agreed that the government should promote donation, and 36% agreed with the statement. Only 7% were neutral, 4% disagreed, and 1% strongly disagreed that the government effort is appropriate. Among the general public group, half as many (25%) strongly agreed, and 35% agreed with the statement – still a majority in agreement, but clearly not as strongly in favor of the federal effort. 25% of the public group was neutral, 12% disagreed with the statement, and 1% strongly disagreed.

The difference in the responses between the two groups was found to be statistically significant, with a P-value of <0.001.

Question 6

6. The perception that wealthy or famous people somehow jump to the top of the transplant waiting list keeps many people from donating organs.

Strongly Agree Agree Neutral Disagree Strongly Disagree

One of the longest-standing controversies in organ transplantation is addressed in this question. Since the shortage of donor organs became a commonly accepted fact, the transplant community has been forced to deal with this myth. Transplant waiting lists and priorities are determined by medical criteria and geography, not by fame or fortune. However, those who can afford to list themselves at multiple transplant centers or travel and wait for a transplant far from home may not have to wait as long if their condition is serious enough. When celebrities are transplanted, the hospital will invariably be faced with questions regarding the listing process – many of which can't be answered unless the patient allows the release of detailed medical information. An important distinction on this question was that it was asking about the impact of the perception of "list-jumping" – not if the respondent individually believed that wealthy/famous people get priority over those who were neither.

Among those employed in transplantation, 5% strongly agreed that this perception was inhibiting donation, and 43% agreed. So, nearly half of this group believes that people may withhold donation on the premise that their donation will not be distributed fairly. 25% were neutral, 22% disagreed, and 4% strongly disagreed. The general public group viewed the question similarly, with 11% who strongly agreed, and 32% who agreed with the statement. 26% were neutral, 28% disagreed, and 2% strongly disagreed.

Question 7

7. I've considered my own wishes regarding organ donation.

Yes No

The purpose of this question was to evaluate the whether the respondents had decided how they would like their own organs to be treated at the time of death. As a critical first step in promoting organ donation, potential donors must first conclude that they would want to donate. The survey did not contain a question asking about the donor status of the respondent because the author did not believe that status would provide meaningful insight into the communications issues reviewed in this project. The issue in this question is not about the specific desires of the respondent, only whether or not they have conducted the exercise of thinking about the subject and making a decision for or against donation.

The vast majority of respondents in both groups have considered their own preferences regarding organ donation. Among those employed in transplantation, 99% answered yes to the question, and 1% answered no. In the general public group, 89% answered yes, 11% answered no. In light of surveys like the 1999 Pew study cited earlier that showed over 80% of the general public is supportive of organ donation, there could be many future organ donors among respondents of this study.

For this question, the chi-squared statistic was 25.8 with 1 degree of freedom. The P-value associated with that statistic was <0.001, which indicates that the difference between the groups was statistically significant. The computerized statistical program

(SPSS) provided a warning that The Fisher's Exact test should be run to calculate the exact P-value. The Fisher's Exact probability was P= <0.001, which confirmed the statistical significance.

Question 8

8. I've discussed my feelings about organ donation with my family.

Yes No

This is the key link in organ donation communications, and one that is still problematic for the transplant community. Undoubtedly there have been situations where a family has not donated the organs of a deceased loved one specifically because they were not aware of how that person felt about donation. Conversely, the author has interviewed many donor family members who noted that their knowledge of the desire of their loved one to donate overrode any previous plans. Recent campaigns promoting organ donation feature the tagline "Share your life. Share your decision." This directly targets the reality that there is a two-step process to donation, and without the consent of next-of-kin, organs are rarely, if ever, recovered for transplantation.

Among those employed in transplantation, 96% have discussed their feelings about organ donation with those who would be faced with the final decision, and 4% have not had that discussion. In the general public group, there is a communications gap on this question. 66% of respondents say they have discussed their wishes about donation with their family, and 34% have not. This response may illustrate that only part of the message about donation – that there is a shortage of donors – is clearly understood. The part of the message that can actually trigger a donation - discussing it with family – is only being acted upon by two-thirds of the target audience. The potential impact of this gap is significant. If the 80% pro-donation Pew number is applied to this question, then over one-quarter of people who want to become donors (80% of the 34%) haven't told their families of their desire to do so. With an average of 3.6 organs recovered per deceased donor, many people in desperate need of a transplant could benefit from these family discussions taking place.

For this question, the chi-squared statistic was 73.7 with 1 degree of freedom. The P-value associated with that statistic was <0.001, which indicates that the difference between the groups was statistically significant. The computerized statistical program (SPSS) provided a warning that The Fisher's Exact test should be run to calculate the exact P-value. The Fisher's Exact probability was P= <0.001, which was statistically significant.

Question 9

9. I have seen/read/heard advertisements promoting organ donation.

Yes No

This question was designed to assess the penetration of organ donor awareness messages through print and broadcast placement, billboards, bumper stickers, posters, internet – any media environment used to promote donation. Referring again to the 80% pro-donation (Pew, 1999) data, one could reasonably inquire as to the usefulness and cost-effectiveness of pursuing the other 20%, but the answer to the previous question of this survey shows that there's still important communicating to be done with people who *want to* donate.

Among those employed in transplantation, there were no surprises – 96% of this group reported an exposure to advertising promoting organ donation, and 4% said they hadn't seen such ads. In the general public group, 55% have seen, read, or heard an advertisement about organ donation, and 45% have not. When considered against other public health initiatives, such as wearing seat belts or not driving while intoxicated, it would appear that the cause of organ donor awareness was not as widely recognized.

For this question, the chi-squared statistic was 103.2 with 1 degree of freedom. The P-value associated with that statistic was <0.001, which indicates that the difference between the groups was statistically significant. The computerized statistical program (SPSS) provided a warning that The Fisher's Exact test should be run to calculate the exact P-value. The Fisher's Exact probability was P= <0.001, which was statistically significant.

Question 10

10. Who (if anyone) was featured in the ad(s) you saw, read, or heard?

______Non-celebrity awaiting a transplant
______Non-celebrity who had a transplant
______A celebrity awaiting a transplant
______A celebrity who had a transplant
______A celebrity who simply supported the cause
______Any government official
______Other (describe)______________________________

The purpose of this question was to get a snapshot of the frequency of use of certain types of spokespeople for organ donor awareness. The categories of people used most often in these ads were listed in the question, and multiple responses were allowed. Responses not falling into any of the listed categories were captured through the use of a text input field. Many respondents who said that they had seen, read, or heard ads promoting organ donation did not answer this question, either because they couldn't remember who they saw, or didn't want to take the time to type in a description if their desired choice was not in the main list. Among those who were familiar with the ad category and responded to this question, there was only one substantial difference between the two study groups.

Among those employed in the field of transplantation, 89% of those had seen, read, or heard advertising for organ donation recalled a non-celebrity awaiting a transplant as the spokesperson, 100% recalled seeing a non-celebrity who had a transplant, 19% reported the use of a celebrity awaiting a transplant, 69% recalled the use of a celebrity who had a transplant, 54% saw a celebrity who simply supported the cause, 41% saw a local, state, or federal government official, and 19% selected "other." Some of the write-in responses for those selecting this option: *donor family member, recipient family, actors, general information-no people, the Grim Reaper being made fun of.* Among those in the general public group, 89% of those had seen, read, or heard advertising for organ donation recalled a non-celebrity awaiting a transplant as the spokesperson, 100% recalled seeing a non-celebrity who had a transplant, 18% reported the use of a celebrity awaiting a transplant, 39% recalled the use of a celebrity who had a transplant, 48% saw a celebrity who simply supported the cause, 22% saw a local, state, or federal government official, and 29% selected "other." Among the write-in responses in this category: *child awaiting a transplant, organ donor family, friends of recipient, no people in the ad.* These results show the strong usage of non-celebrities in the promotion of organ donation, and since only a few of the transplants performed every year are on celebrities, this appears to be a useful strategy. The use of celebrities, as discussed previously, can have some associated risks. Though the recognizable name and face can attract attention, the data show that celebrities are not used as frequently, are not as well remembered, or both.

Question 11

11. The advertisement that I saw/read/heard caused me to consider my own feelings about organ donation.

Strongly Agree Agree Neutral Disagree Strongly Disagree

Among those who recalled seeing, reading, or hearing an ad for organ donation, this question addresses one of the possible effects of that communication on the respondent. Did the ad create a clearly defined action – the consideration of the respondent's individual feelings about organ donation – or did it have little or no effect? In many cases, the respondents may have already decided to become organ donors, so an ad suggesting that wouldn't have any effect. For those who were unsure, or perhaps against donation, exposure to a pro-donation message may have triggered the consideration process of a change in position.

In the group of people employed in transplantation, 13% strongly agreed that the ad they saw, read, or heard directly caused them to consider their feelings about organ donation, and 35% agreed, meaning that nearly half of survey respondents in this group were moved by an advertisement they saw about something that they were extremely familiar with (their job). 36% were neutral, 15% disagreed, and 1% strongly disagreed with the statement. It seemed as if these results could be a validation of the effectiveness of these ads – after all, if you can get people thinking about something that they already know all about, you have a meaningful communications tool. However, the results among the general public group were very similar to the transplant group. 7% strongly agreed, and 47% of the general public group agreed with the statement, so slightly more than half of people who are not exposed to organ transplantation issues on a daily basis reported that seeing a pro-donation ad caused consideration of their own feelings. If only half of your target audience is acting on your message, there is clearly room for a greater impact. 32% of the general public group was neutral, 13% disagreed, and 1% strongly disagreed with the statement.

Question 12

12. The advertisement that I saw/read/heard made me more likely to become an organ donor.

Strongly Agree Agree Neutral Disagree Strongly Disagree

This question explores the desired result of these ads – that the viewer will understand the urgency and make the emotional commitment to becoming an organ donor. This is the most direct measurement of the effectiveness of the ads. Though the initiation of the thought process about organ donation addressed in the previous question is fundamental, Question 12 is where the "sale" is closed – the respondent is saying that the ad actually changed their thinking about the issue in the direction desired by the advertiser. If increasing organ donation through advertising is to be considered a worthwhile expenditure of time and money, the results of this question should be compelling. Unfortunately, the results are similar to those of the previous question for both groups.

Among those employed in transplantation, 11% strongly agreed that the ad they saw made them more likely to become an organ donor, and 33% agreed. 36% were neutral, 18% disagreed, and 2 strongly disagreed with the statement. Again, considering the fact that there are few, if any jobs in the field of organ transplantation that do not involve some effort at promoting the cause, over 40% of this group stating that an ad they saw about something they clearly understood previously actually moved their mindset on the subject is an impressive result. The general public group showed 9% strongly agreed, and 41% agreed with the statement, leaving half of the target audience (34% neutral, 16% disagreed, 0% strongly disagreed) without a positive change in their position. This result helps explain why so many media impressions from public service announcements don't seem to be making a meaningful difference in deceased donor organ donation rates.

Question 13

13. Providing a financial incentive to families such as reimbursing funeral costs would increase the chances of obtaining consent for organ donation at the time of death of their loved one.

Strongly Agree Agree Neutral Disagree Strongly Disagree

As reviewed in Chapter 2, the use of financial incentives as a mechanism to increase deceased donor organ donation has been a topic of heated debate in the transplant community and in the general public. This question evaluates the opinions of survey respondents regarding the usefulness of this type of program as something that might make a difference in reducing the donor organ shortage. While there are a variety of financial incentives that have been discussed over the years, reimbursement of funeral expenses is the most easily understood in that regard. The results on this question show broad support for this approach.

Among those employed in organ transplantation, 13% strongly agreed that financial incentives would increase the rate of deceased donor organ donation, and 44% agreed – a clear majority among those who are deeply involved in the process. 20% were neutral, 15% disagreed that there would be a benefit to this approach, and 8% strongly disagreed. The support for financial incentives was even stronger among the general public. 21% strongly agreed with the statement, and 47% agreed – meaning that over two-thirds of the respondents in this group saw the potential impact that a financial incentive could have on the likelihood of donation. 14% were neutral, 16% disagreed, and 2% strongly disagreed with the statement. The efforts to promote financial incentives have been hampered by the fact that the transplant legislation awaiting President Bush's signature contains no funding to test the use of this technique, but clearly the respondents of this survey believe the concept has merit.

The difference in the responses between the two groups was found to be statistically significant, with a P-value of <0.004.

Question 14

14. The federal government's effort to increase organ donation is an example of:

_____a meaningful and beneficial use of tax dollars that will help save many lives

_____a well-intentioned effort that may help somewhat over time

_____another government program that will not improve the situation

_____I don't know enough about this to have formed an opinion

The US Secretary of Health and Human Services is the Cabinet official who is responsible for organ donation, allocation, and transplantation policies. Tommy Thompson, the current Secretary of HHS, has been a strong advocate for organ donation for many years, and brought a renewed focus to the issue shortly after taking office in 2001. Funding for research projects on increasing organ donation was increased exponentially, and efforts included a major initiative into promoting organ donation with the cooperation of some of the nation's largest employers, studying ways to increase organ donation among minorities, the usefulness of organ donor registries, and many other projects. This question sought a subjective evaluation of this effort. The initial version of the survey only included the first three choices. After preliminary testing of the survey instrument, the "don't know enough about it" choice was added – many testers simply wrote that on the survey forms.

Within the transplant community, the Dept. of HHS gets moderate support – 33% believe this effort is "a meaningful and beneficial use of tax dollars that will help save many lives." Over half of this group (53%) can be considered somewhat skeptical, selecting "a well-intentioned effort that may help somewhat over time." Only 7% rated the initiative as "another government program that will not improve the situation," and 6% didn't know enough about it to have formed an opinion. Among the general public, 22% chose "a meaningful and beneficial use of tax dollars that will help save many lives," 37% felt that this was "a well-intentioned effort that may help somewhat over time," and 11% were not impressed, calling it "another government program that will not improve the situation." The remaining 30% of the general public group said that they did not know enough about this to have formed an opinion – presumably a number that the Dept. of HHS would like to reduce.

Question 15-16

15. (transplant group only) Presumed consent is a good idea that could help reduce transplant waiting lists in the US.

Strongly Agree Agree Neutral Disagree Strongly Disagree

16. (transplant group only) Presumed consent will never be implemented in the US.

Strongly Agree Agree Neutral Disagree Strongly Disagree

Questions 15-16 were seen only by those who are employed in organ transplantation, inquiring about one of the controversies in transplantation discussed earlier. The survey conducted among 739 members of the International Society for Heart and Lung Transplantation (Oz, 2002) showed very strong support for presumed consent (75%). The results from the smaller group here showed 28% strongly agreed with the statement, and 34% agreed – still a solid majority in favor of this approach to increasing deceased donor organ donation. 17% were neutral, 14% disagreed, and 7% strongly disagreed that presumed consent was a good idea. A majority also felt that presumed consent would never be implemented in the US – 13% strongly agreed, and 42% agreed with this statement. 26% were neutral, 15% disagreed, and 2% strongly disagreed. The surprise here is that nearly 1 in 6 transplant professionals – knowing the ethical, legal, regulatory, and medical challenges that the US legal system and health care environment would pose to presumed consent – believe that it will indeed be used in this country someday.

Question 17

17. (non-transplant group only) I know someone who has received an organ transplant.
Yes No

This question was inserted to assess the familiarity of those not employed in organ transplantation with the field through personal knowledge of someone who received a solid organ transplant. 42% of this group said they did know someone who had a transplant, and 58% said they did not. It is possible that people who are transplant recipients submitted some of the "yes" answers.

Chapter 5 – Conclusions

After more than 15 years of working in the field of solid organ transplantation, the author has been exposed to many of the major issues and advances in the field – from organ allocation controversies and surgical innovations to donor family concerns and immunosuppressive therapy breakthroughs. As a professional communicator who frequently produced programs designed to promote organ donor awareness, the author was always optimistic that those efforts were measurably helpful to the cause, though there was nothing more than limited anecdotal evidence in that regard. After conducting the historical review and attitude survey, the primary conclusion is that the positive benefits of solid organ donation have been established in the public conscience to the extent that large-scale public awareness campaigns don't provide meaningful and sustainable improvements in deceased donor organ donation rates. This is a difficult position to take for someone who has long been involved in the conceptual development and creation of these programs.

When evaluating the numerous aspects of solid organ transplantation to isolate one that could truly make a difference in increasing deceased donor solid organ donation, the author believes that reducing the number of prospective donor families who are never asked about donation, and improving the processes and techniques for obtaining consent from those who are asked would be more beneficial to patients awaiting a life-saving transplant than distributing more Public Service Announcements encouraging organ donation.

The efforts of the US Dept. of Health and Human Services Advisory Committee on Organ Transplantation (ACOT) reinforce the reduced priority on public awareness efforts. Of the first 28 recommendations made by this carefully selected group of experts, not one was aimed specifically toward increasing awareness among the general public of the need for more organ donors. (US Dept. of HHS, 2003) A study in progress and funded through a grant from the Division of Transplantation is exploring the impact of combining traditional mass media communications about organ donation with interpersonal interventions on the campuses of six large universities. (US Dept. of HHS, 2002) If this approach is shown to make a significant difference in the rate of signed organ donor cards and discussing the subject with family members (the key outcome measurements), the entire process of donor awareness communications will hopefully begin to experience a paradigm shift away from primarily passive, distant forms to active, up-close and personal techniques.

The results from the attitude survey conducted for this project affirm the high recall rates of some commonly used styles in donor awareness campaigns, particularly the use of non-celebrities who received an organ transplant. The 2004 Coalition on Donation PSA campaign features seven recipients and one person waiting for a transplant. But the effectiveness of these ads, and all the other regionally and locally produced media with the same message, will be faced with a challenge from the 50% of respondents within the general public group in this survey that saw, heard, or read an ad about organ donation that did not make them more likely to become an organ donor.

The difficulties associated with causally linking a specific public awareness campaign with measurable improvements in donation rates are numerous. A person - let's call him John Winston - would need to have seen an advertisement promoting organ donation, make the decision to become an organ donor based on that ad, then not only tell their family that they wished to be an organ donor, but also that they made that decision based on the ad they saw. The Winston family member who made the decision to allow the organ recovery at the time of John's untimely death would have to remember that it was the ad that helped John make his decision, and report that fact to the person making the request for organ donation. Another possibility is that John Winston never discussed donation with his family, but one of his relatives saw an ad promoting donation, and convinced the rest of the family that it was the right thing to do. This circumstance would also have to be reported to the requestor. That person – presumably an OPO staffer – would have to collect this data during a predetermined period of time that followed the initiation of the public awareness campaign. Then the number of deceased donor organ donation consents given where the ad was mentioned as the impetus for donation would have to be compared to the number of consents given where the same ad wasn't mentioned – then a data-driven claim could be made about the effect of the campaign on organ donation.

With the federal budget deficit appearing frequently in the news, the use of tax dollars to improve the overall environment for people who need a transplant remains a noble goal, but it seems that the Dept. of HHS will need to show consistently positive results before the transplant community is fully supportive. The general public group in this study, with nearly one-third unaware that the government was making this effort, needs information first, followed by results. Organ transplantation has good friends in high places, with current US Senate Majority Leader William Frist and the Secretary of HHS Tommy Thompson leading the way when possible. Directing the intellectual effort and financial resources of public and private institutions to those endeavors that can help provide a measurable, direct, and sustainable improvement in deceased organ donation will represent the true measure of success desired by everyone involved in the field of organ transplantation as well as the 85,000 people in the US waiting for a life-saving organ transplant.

Appendix – Author's Experience in Transplant Communications

1988-1995: *Producer, Sandoz Pharmaceuticals Corp.* Produced physician and patient education video programs on immunosuppressive therapy, history of transplantation, organ donor awareness.

1989-present: *Executive Producer, US Transplant Games.* Supervise the production of all video coverage of the US Transplant Games, since 1995 as a volunteer to the National Kidney Foundation.

1996-2003: *Co-Producer, Transplant Video Journal.* Developed and produced a quarterly video news magazine on organ transplantation issues. Topics covered included allocation issues, surgical techniques such as laparoscopic live-donor nephrectomy, non-heart beating donors, transplantation and pregnancy, donor registries, AST/ASTS meetings, new immunosuppressants, etc.

Produced programs on transplantation for the following companies and organizations:

North American Transplant Coordinators Organization
National Donor Family Council
National Kidney Foundation
American Liver Foundation
Novartis Pharmaceuticals
Roche Laboratories
Organ Recovery Systems
Transplant Recipients International Organization

Bibliography

The Alpha-1 Foundation. (2003). *Special Stories: Trine Engebretsen.* Retrieved March 15, 2004 from www.alphaone.org/alpha1/special_stories/trine.html.

American Liver Foundation. (2004). *ALF Transplant Fund Program.* Retrieved March 15, 2004 from http://www.liverfoundation.org/db/articles/1029.

American Medical Association. (1994) *Code of Ethics E-2.155 Mandated Choice and Presumed Consent for Cadaveric Organ Donation.* Retrieved March 23, 2004 from http://www.ama-assn.org/ama/pub/category/8446.html.

Armitage, J.M., et al. (1991). The clinical trial of FK 506 as primary and rescue immunosuppression in cardiac transplantation. *Transplant Proceedings, 23*:1149-1152.

Asfar, S., et al. (1996). Small bowel transplantation. A life-saving option for selected patients with intestinal failure. *Digestive Disease Science, 41(5)*:875-883.

Associated Press. (1999). *Doctors: Transplant Not Possible for Payton.* USA Today. November 1, 1999. Retrieved March 22, 2004 from http://www.usatoday.com/sports/nfl/walt/waltfs06.htm.

Borel, J.F., Feurer, C., Gubler, H.U., & Stahelin, H. (1976). Biological effects of cyclosporin A: a new antilymphocytic agent. *Agents and Actions,* 6:468-475.

Broelsch, C.E., et al. (1990). Application of reduced-size liver transplants as split grafts, auxiliary orthotopic grafts, and living related segmental transplants. *Annals of Surgery, 212*, (3):368-75.

Calne, R.Y., et al. (1979) Cyclosporin A initially as the only immunosuppressant in 34 recipients of cadaveric organs: 32 kidneys, 2 pancreases, and 2 livers. *Lancet,* 2:1033-1036.

Carrel, A. (1914) The transplantation of organs. *New York Medical Journal,* 99:839-851.

DeGette, Diana. (2003). Statement of US Rep. Diana DeGette (D-CO). Hearings before the Subcommitee on Oversight and Investigations, Committee on Energy and Commerce, US House of Representatives, June 3, 2003. Retrieved on March 3, 2004 from http://energycommerce.house.gov/108/Hearings/06032003hearing946/print.htm.

Demetris, A.J., et al. (1991). Histopathology of human renal allograft rejection under FK 506: A comparison with cyclosporine. *Transplant Proceedings, 23,* 944-946.

Derom, F., et al. (1971). Ten-month survival after lung homotransplantations in man. *Journal of Thoracic Cardiovascular Surgery, 61,* 835-846.

The Donor Foundation. *Milestones in Transplantation*. Retreived March 15, 2004 from http://www.donorfoundation.org/articles/first.htm.

Food and Drug Administration. Query on "cyclosporine." Retrieved March 15, 2004 from http://www.fda.gov/cder/ob/docs/queryai.htm.

Gahrton, Gösta. (1990). Nobel Prize in Physiology or Medicine. Presentation Speech to Joseph Miller, MD. Translation from the Swedish text. Retrieved March 15. 2004 from http://www.nobel.se/medicine/laureates/1990/presentation-speech.html.

Green, John. (2002). Philadelphia Region Leads Nation in Number of Organ Donors and Transplants in 2002 -- Largest number of transplants ever recorded in nation. Web story retrieved on March 23, 2004 from http://www.donors1.org/news/2002_numbers.html.

Greenwood, James. (2003). Statement of US Rep. James Greenwood (R-PA). Hearings before the Subcommitee on Oversight and Investigations, Committee on Energy and Commerce, US House of Representatives, June 3, 2003. Retrieved on March 3, 2004 from http://energycommerce.house.gov/108/Hearings/06032003hearing946/print.htm.

Groote Schuur Hospital. *Transplanting Life: The Story of Chris Barnard.* Retrieved March 15, 2004 from http://www.gsh.co.za/ab/heart.html.

Hamilton, D.N.H., Reid, W.A. (1984). Yu Yu Voronoy and the first human kidney allograft. *Surgical Gynecology and Obstetrics, 159,* 289-294.

Hoffenberg, R. (2001). Christiaan Barnard: his first transplants and their impact on concepts of death. *British Medical Journal, 323*, 1478.

Hollreiser, Eric. (1996). *Transplant plan hopes potential donors like Mike.* Philadelphia Business Journal, November 1, 1996. Retrieved on March 22, 2004 from http://philadelphia.bizjournals.com/philadelphia/stories/1996/11/04/story7.html?t=printable.

Homer, Mark. (2003) *An act relating to presumed consent to human organ donation.* State of Texas House Bill No. 2111. Retrieved March 22, 2004 from http://www.capitol.state.tx.us/cgi-bin/tlo/textframe.cmd?LEG=78&SESS=R&CHAMBER=H&BILLTYPE=B&BILLSUFFIX=02111&VERSION=1&TYPE=B.

Ingelhart, Ronald F. (1997). Study of worldwide rates of religiosity, church attendance. University of Michigan Press Release, December 10, 1997. Retrieved on March 22, 2004 from http://www.umich.edu/~newsinfo/Releases/1997/Dec97/r121097a.html.

Institute of Medicine. (1999). *Assessing Current Policies and the Potential Impact of the DHHS Final Rule.* Washington, DC. National Academy Press.

Katz, Stuart. (2003) Personal recollections/archives of the author.

Kefalides, Paul. (1998). Solid organ transplantation. *Annals of Internal Medicine, 129,* 1093-1095.

Kerbaj, Richard. (2004) *Abbott vows to increase organ donor rates.* The Age On-line. Retrieved March 23, 2004 from http://www.theage.com.au/articles/2004/01/03/1072908953390.html?from=storyrhs.

Klintmalm, G.B. (1996). Clinical use of FK 506 in liver transplantation. *Transplant Proceedings, 28(2),* 974-6.

Knox, Richard A. (1997). The Dawn of High-Tech Healing. *Boston Globe.* Retrieved March 15, 2004 from www.boston.com/globe/specialreports/ /mar/125/1954.htm.

Kolata, Gina. (1996) Acrimony at Hearing on Revising Rules for Liver Transplants. *New York Times.* Retrieved March 15, 2004 from http://www.mc.vanderbilt.edu/surgery/liver/News/news-acrimony.htm.

Kuss, R., Legrain, M., Mathe, G., Nedey, R., & Camey, M. (1962). Homologous human kidney transplantation. Experience with six patients. *Postgraduate Medical Journal, 38,* 528-531.

Lee, P., Murase, N., Todo, S., Makowka, L., & Starzl, T. (1987). The immunosuppressive effects of FR 900506 in rats receiving heterotopic cardiac allografts. *Surgical Research Communication, 1,* 325-331.

LifeSharers. Main web page. Retrieved on March 23, 2004 from http://lifesharers.com.

Loma Linda Medical Center. (1999). Leonard Bailey, world-renowned heart surgeon, remembers with fondness a tiny baby named Fae. Retrieved March 15, 2004 from http://www.llu.edu/news/today/dec299/mc.htm.

Lower, Richard, and Shumway, Norman. (1960). Studies on Orthotopic Homotransplantation of the Canine Heart. *Surgical Forum,* American College of Surgeons.

Mantle, Mickey. (1995). Organ Donor Card distributed by the Mickey Mantle Foundation, Dallas, TX.

McLellan, Dennis. (2003). Obituary: Wendy Marx, 36; championed awareness of organ donation. *Los Angeles Times.* October 31, 2003.

McMenamin, Brigid. (1996, March 11). The Organ King. *Forbes.*

Medical News Report. (1995). *Mickey Mantle transplant: Battling perceptions of preferential treatment.* Retrieved March 22, 2004 from http://www.medicalnewsreport.com/med9507.htm.

Merion, R.M., White, D.J.G., Thiru, S., Evans, D.B., & Calne, R.Y. (1984) Cyclosporine: Five Years' Experience in Cadaveric Renal Transplantation. *New England Journal of Medicine, 310,* 148-154.

Michon, L., Hamburger, J., Oeconomos, N., et al. (1953). Une tentative de transplantation renale chez l'homme. *Aspects Medicaux et Biologiques, 61,* 1419-1423.

Mid-West Eye Banks. (2000). Scriptures that may be useful for the subject of organ and tissue donation. Listing on web site. Retrieved on March 22, 2004 from http://www.mebtc.org/sabbath00c.htm.

National Kidney Foundation. (1990) Fact Sheet: The 1990 US Transplant Games. Personal archives of the author.

Organ Procurement and Transplantation Network. (2004a, c, i) *OPTN/SRTR Annual Report.* Table 1.3: Waiting List at End of Year, 1993-2002. Report generated at: http://www.optn.org/AR2003/default.htm.

Organ Procurement and Transplantation Network. (2004b) *OPTN/SRTR Annual Report.* Table I-3: Unadjusted 1 and 5-year Patient Survival by Organ. Report generated at: http://www.optn.org/AR2003/default.htm.

Organ Procurement and Transplantation Network. (2004d, e) *OPTN/SRTR Annual Report.* Table 1.1: US Organ Donors by Organ and Donor Type. Report generated at: http://www.optn.org/AR2003/default.htm.

Organ Procurement and Transplantation Network. (2004f, g, h). *Transplant:Transplant Year by Donor Type, US Transplants Performed Jan. 1, 1988 – Aug. 31, 2003.* Report generated at: www.optn.org/data.

Organ Procurement and Transplantation Network. (2004j) *Death Removals by Region by Year.* Report generated at: www.optn.org/data.

Organ Procurement and Transplantation Network. (2004k, l, m) *Donor: Donation Year by Donor Type.* Report generated at: www.optn.org/data

Oz, Mehmet C., et al. (2003). How to improve organ donation: results of the ISHLT/FACT poll. *Journal of Heart and Lung Transplantation, 22,* 4:389-410.

Presumed Consent Foundation. (2003). *Solutions.* Web page. Retrieved on March 23, 2004 from http://www.presumedconsent.org/solutions.htm.

Pew Research Center for the People & the Press. (1999) Survey conducted by Princeton Survey Research Assoc. May 12-16, 1999. N=1,013 adults nationwide.

Reitz, B.A., et al. Heart-lung transplantation: successful therapy for patients with pulmonary vascular disease. *New England Journal of Medicine, 306,* 557-564.

Robeznieks, Andis. (2003). *Texas mulls policy for organ donation by presumed consent.* American Medical News. April 28, 2003. Retrieved March 23, 2004 from http://www.ama-assn.org/amednews/2003/04/28/prsd0428.htm.

Rossi, Lisa. (2003). Artificial Liver Being Tested at Univ. of Pittsburgh Used Successfully in Two Patients So Far. University of Pittsburgh Medical Center press release, February 3, 2003.

Rutecki, Gregory W. (2003). *Human Dignity and the Organ Supply: Do Proposed Solutions to the Current Crisis Measure Up?* Center for Bioethics and Human Dignity web page. Retrieved on March 23, 2004 from http://www.cbhd.org/resources/healthcare/rutecki_2003-02-11_print.htm.

Sanchez, Julian. (2003). *Whose organs are they, anyway?* Reason On-line. Retrieved March 23, 2004 from http://www.reason.com/hod/js062603.shtml.

Siminoff, L.A., Arnold, R.M., & Hewlett, J. (2001). The process of organ donation and its effects on consent. *Clinical Transplantation, 15,* 39-47.

Starzl, Thomas. (1996) Foreword to *Transplantation of the Liver*
Edited by Ronald W. Busuttil and Goran B. Klintmalm. Philadelphia, W.B. Saunders.

Starzl, T.E., et al. (1963). Homotransplantation of the liver in humans. *Surgical Gynecology and Obstetrics, 117,* 659-676.

Starzl, T.E., et al. (1980). The use of cyclosporin A and prednisone in cadaver kidney transplantation. *Surgical Gynecology and Obstetrics, 151,* 17-26.

Starzl, T.E., et al. (1989). Transplantation of multiple abdominal viscera. *Journal of the American Medical Association, 261,* 1449-1457.

Starzl, T.E., Kaupp, H.A. Jr., Brock, D.R., Lazarus, R.E., Johnson, R.V. (1960) Reconstructive problems in canine liver homotransplantation with special reference to the postoperative role of hepatic venous flow. *Surgical Gynecology and Obstetrics, 111,* 733-743

Stoller, Kenneth P. (1990) Baby Fae: The Unlearned Lesson. *Perspectives On Medical Research Volume 2.* Americans for Medical Advancement. Retrieved March 15, 2004 from http://www.curedisease.com/Perspectives/vol_2_1990/BabyFae.html.

Summit Consulting Group, Inc. (1999) *Playing to Win in the Public Arena.* Claim on web site. Retrieved March 22, 2004 from http://www.summitconsult.com/arena/success.html.

Texas Medical Association. (2003). *2003 Legislative Compendium: Transplantation/Organ Donation.* Retrieved on March 23, 2004 from http://www.texmed.org/pmt/lel/cln/com03/tod.asp.

Town Crier, Wellington, FL. (2001). "Group Hopes To Find More Organ Donors,"Accessed at http://www.thecrier.com/archive/leadnews7Dec2001.htm.

UNOS. (2002) Liver Policy Outcomes Encouraging at Six Months; Some Adjustments Recommended. Press release on November 13, 2002.

UNOS. (2003). Coalition on Donation. Retrieved on November 22, 2003 from http://www.unos.org/helpSaveALife/promoteOrganDonation/coalitionOnDonation.asp.

URN. (2004) Home web page of United Resource Networks. Retreived on April 10, 2004 from http://www.urnweb.com/index.htm

US Dept of Health and Human Services. (1998). HHS Rule Calls for Organ Allocation Based on Medical Criteria, Not Geography. Press Release on March 26, 1998.

US Dept of Health and Human Services. (2003). Advisory Committee on Organ Transplantation. Summary Notes from Meeting, Washington, DC. November 6-7, 2003. Retrieved on April 10, 2004 from http://www.organdonor.gov/acot11-03.html.

US Dept of Health and Human Services. (2002). Extramural Grant Program, FY 2002 Grantees. Retrieved April 10, 2004 from www.organdonor.gov/fy2002awards.htm.

US Senate. (2003). S. 573. *Organ Donation and Recovery Improvement Act.* Retrieved on March 22, 2004 from http://thomas.loc.gov/cgi-bin/query/D?c108:3:./temp/~c108Inb9Ew::.

Wendy Marx Foundation. (2003) "About the Wendy Marx Foundation for Organ Donor Awareness" Retrieved on March 22, 2004 from http://www.transplantbook.com/foundation.html.

Wiggins, Ovetta. (2002). *PA. organ donors get $300 boost.* Philadelphia Inquirer On-line. Posted May 27, 2002. Retrieved on March 22, 2004 from http://www.philly.com/mld/inquirer/3346239.htm.