

94 PERCENT AWARENESS AND STILL NOT ENOUGH DONORS

CAN PUBLIC EDUCATION INCREASE ORGAN DONATION?

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Introduction

Every public opinion survey regarding organ donation and transplantation shows one undisputed fact: the American people are very aware of organ donation. They always respond at rates over 90 percent to questions about awareness. Yet, the donor shortage goes on. Something must still be needed that will translate awareness into a larger supply of organs.

This paper explores the role of public education in that relationship. It looks at what we in the transplant community have done to educate the public and what we would like to do. It also examines some of our basic assumptions and some of the conventional wisdom which has guided our planning. It isn't possible to calculate the amount of money, time, and energy we have devoted to public education. It has been considerable. We have achieved an awareness of 94 percent (1). That is a major accomplishment. Still, we don't have enough organs.

Can public education increase organ donation? The answer is no, not by itself. It is unrealistic to think that if we could just educate the public more, or better, the shortage would disappear. Public education is important, but it alone cannot increase the supply of organs. Its role is a supportive one, not a primary one. That concept challenges our basic assumptions about what public education can and should do and how we should conduct it.

Why is organ donation so different?

- It is not something you can do yourself.
- It is not something that benefits you at all.
- You cannot cause it to happen.
- It depends absolutely on someone else doing something.
- It is extremely unlikely.
- It occurs only after you're dead.

Traditional health education planning models have to be reconsidered when we apply them to these circumstances.

We usually think of public education in mass terms. But, the really important people are the 12,000 or so families who will be in a position to agree to organ donation next year (2). Campaigning to reach all 250 million Americans is not cost effective when we understand that currently half the families who actually could donate aren't even asked (3).

Public education has to fit within a total effort to raise the supply of organs. That means a concentration on the supportive and maintenance role of public education in allocating a community's scarce resources. A 94 percent awareness rate means the job is maintenance. Education should support the real circumstance of organ donation. That occurs in a hospital waiting room when one family hears one question. That's when we can tell if our education is working. If they've heard of organ donation, talked about it, and know it's what their loved one would have wanted, we've been successful.

The goal of public education is "To maintain a level of public awareness of organ and tissue donation which will favorably dispose families toward donation if they are ever asked to grant permission." Many things have to fall into place in order for organs to be donated. Public education can help the process be successful, but it can't go beyond that. We can't expect families, at that particular time in their lives, to seek the donation opportunity. That's why public education can't increase organ donation; it can only help the process be successful once the process has begun. Until that process begins a lot more frequently, public education will remain a secondary challenge. This does not mean that public education is unimportant. It is, and we're still going to do it. We need to maintain the excellent level of awareness that we've reached.

The time of organ donation opportunity is an emotion-laden, stressful, personal and private part of a family's life. We want our education to have predisposed the family toward agreement. We don't need to give them all the facts or details. We just need to have created the right atmosphere in their minds so that it seems more natural to say yes. To do that we hope they have a sense that:

- Transplantation is "good".
- Organ donation is the "right" thing to do.
- When a person dies "senselessly," the only "good" possible is organ donation.
- The person who died, a "good" person, would have wanted his or her family to do the "right" thing.

If those ideas are the sense of the situation in the family's mind, the process will be successful. Our planning should concentrate on what creates that sense, what reinforces it, and what would work against it. Those questions are the foundation of a new approach to public education.

Our educational framework should be built on a few basic, easily assimilated, simple themes, frequently repeated. We should skip the details; they are too negative, too easily misunderstood and too complicated. We want people to feel that organ donation is good, the "moral" thing to do.

Our mission is not to raise the educational level of the American people. Our mission is to increase the number of organs donated in this country so there can be more transplants. Public education is an important part of that. This Surgeon General's workshop gives us an opportunity to reflect on our successes and our challenges. It should be a catalyst for us to re-examine our thinking, evaluate our assumptions, clarify our intentions and renew our commitment to support our mission with effective public education programs.

Current State of the Art

A 1987 Gallup Poll conducted for the Dow Chemical Company, reported that 94 percent of all Americans were aware of transplantation and organ donation (4). In general, the series of public opinion surveys conducted during the 1980s have consistently reported very high awareness (5). The latest poll, taken in 1991 for the Partnership for Organ Donation, reported that 84 percent of Americans actually support the donation of organs for transplantation (6).

In spite of that high degree of public awareness, the transplant community continues to face a severe shortage in donated organs. In April 1991, the Institute of Medicine released a study of the End Stage Renal Disease Program called for by Congress. In that study, the IOM reports, "Kidney transplantation...is the preferred treatment for a majority of ESRD patients...The major factor limiting access to transplantation is the shortage of available kidneys" (7).

Information revealed in the various polls illustrates the continuing problem:

- "The population is aware of transplantation...People remain supportive of transplantation, yet ambivalent about organ donation" (Battelle, 1987)(8)
- "84% of those aware of organ transplants have heard about organ donor cards" (Gallup, 1986)(9); "20% of those aware have completed an organ donor card" (Gallup, 1987)(10)

- "92% of those aware of organ transplants say they heard about them on TV" (Gallup, 1985)(11)
- "Surveys indicate that the public's awareness of transplantation is high, but its enthusiasm for donation is lower..." (IOM, 1991)(12)
- "67% of those aware of organ transplants see an organ donor as loving, generous person who cares about others. Even among respondents not likely to donate their own organs over half (53%) picture this type of person" (Gallup, 1985)(13)
- "If the family knew of their loved one's wishes, 94% said they would honor the request; if the family members did not know, only 54% would donate the relative's organs" (Gallup, 1991)(14)
- "73% said they would likely want their organs donated upon death. 76% of whites and 45% of blacks" (Gallup, 1991)(15)

These polls describe the public's perception of the relationship it has with the transplant community. We have done a good job of creating and sustaining awareness. However, that awareness hasn't translated into more donation. The IOM points out the inconsistency between polls showing that the public is aware and the worsening shortage, "...the number of all kidney transplants grew an average of 5.5% per year from 1974 through 1978, then at more than 10% annually from 1978 to 1986. Since 1986, however, no growth has occurred, and the numbers have actually decreased slightly" (16).

It is interesting that the trend stopped in 1990. The United Network for Organ Sharing's data reports that the number of transplants actually increased in 1990 over 1989 by 15 percent. That rate was made possible by an increase in cadaver donors of 11 percent. There were 4,357 cadaver donors in 1990; that's up from 3,923 in 1989 (17). It's too soon to tell whether that indicates an upward trend in dealing with the shortage or a one-time uptick.

What is clear is that the number of organs donated does not begin to meet the need for transplants. Those waiting for a transplant has grown to over 23,000 (18). It is also clear that the number of cadaver donors is not anywhere near the number of medically suitable potential donors. The IOM reports, "Actual acquisition may be one-third to one-half the potential pool" (19).

Howard Nathan and associates conducted a study of the donor pool in Pennsylvania and surmised that half of the potential donors were never considered

for donation. He places the size of the potential donor pool at between 38.3 and 55.2 donors per million population per year. If those donations were realized, there could be twice as many donors and more than twice as many transplants (20).

Public education programs exist throughout the United States sponsored by national, regional, and local organizations. Every conceivable tactic is being tried by some organization somewhere. The sponsors of the messages may be totally committed to organ donor education or only marginally interested. The scope of the programs may be national or local, and their content may be coordinated within an area or not. It isn't possible to calculate the dollars being spent or the time being invested in these programs.

Edith Oberley and associates undertook a study of the educational programs underway in 1991 and reported, "Programs continue to be local and uncoordinatedTV is underused and often badly targeted....few programs are minority targeted....no easily identified message....lack of consistency....language levels too high." She describes one unfortunate common denominator of many of the programs: "...public education has often been an afterthought as transplant related organizations have focused on professional education and administrative concerns" (21).

The major national organizations all appear to be planning an increase in their public education programming. UNOS is working with the J. Walter Thompson advertising firm. The Association of Organ Procurement Organizations is working with a design firm on graphic representations of the need for organ donation. Many other programs, such as the Dow/NAACP and the National Kidney Foundation's New Year's Resolution Campaign, are ongoing. Most other national members of the transplant community are committed to public education as well.

Public education requires a large investment of scarce resources. Organizations can benefit from exchanging ideas before developing expensive programs. Programs are more effective when they are planned and developed in a coordinated fashion and supported by the shared experience and knowledge of all those interested. Sharing would also facilitate clarity and consistency in messages which are currently diverse.

The UNOS Board of Directors approved a resolution that UNOS "participate in the formation of a multi-member coalition to coordinate national efforts in order to improve organ donation throughout the United States" (22). UNOS bases its concept on its current clearinghouse which compiles information on past and present educational efforts. This expansion would not replace the current planning processes and needs of the large and diverse group of member organizations. To

be successful, the consortium would not compete with its members for funds or public recognition, nor would it seek funding or conduct its own programs. It would serve as a clearinghouse for future programs in public education.

Historical Analysis and Evaluation of Organ Donation Education Programs

Transplantation began to make headlines in 1954 with the exciting news that a kidney had been successfully transplanted between two individuals (23). The identical twin transplants were one of the scientific breakthroughs of the 50s. The Reader's Guide to Periodical Literature reports that 19 articles on the subject of transplantation appeared in 1954 alone (24). Twenty-five more articles appeared in the next 2 years (25). Typical was an article in Good Housekeeping entitled "Spare Parts for the Human Body" (26). Identical twin transplants, followed by closely related living donors, were the only procedures commonly done before 1964.

Interest in transplantation grew as the operations became more common, especially when they began to involve non-living donors. The Reader's Guide shows the average number of articles per year increased from 13 during the late 50s to 34 in the 60s (27). This coincided with the launch of a campaign to pass the Uniform Anatomical Gift Act (UAGA) in the late 60s. Medical and lay organizations enlisted public support in getting the measure adopted by all 50 States. That was accomplished by 1969 following an all-time high in magazine articles of 85 in 1968 (28).

One of the most publicized events in the history of transplantation was the first heart transplant in 1967 (29). Extensive media coverage from Capetown, South Africa was a major landmark in making the public aware of organ donation and transplantation as a clinical therapy. This boosted the early efforts to gain public support through donor cards which were made possible by the UAGA.

The National Kidney Foundation, the American Medical Association and other groups began a major effort to distribute donor cards in the early 1970s. Signing a donor card became a theme of most efforts to reach the public about organ donation. Thousands of cards were distributed at health fairs, in grocery bags, in direct mail pieces and as part of fund raising campaigns. They became the focus of television public service announcements, posters, billboards and even stickers saying "I Love You... With All My Kidney."

Another landmark was the inclusion of transplantation and dialysis in the Medicare program in 1972. This coverage stimulated a phenomenal growth in the number of people waiting for a transplant. When the program began in 1973, 15,000

Americans were on dialysis. Today that number exceeds 115,000. The demand for transplantation and the mechanism for paying much of its costs grew out of the one sentence addition to PL 92-603 (30).

Another catalyst for public awareness of transplantation was television star Gary Coleman. For several seasons one of NBC's most popular shows was *Diff'rent Strokes*, starring the 4' 9" Coleman. Much media attention was focused on the fact that Coleman had received two kidney transplants by the time his show entered syndication (31). Coleman discussed his transplants and the need for organ donation on talk shows and in interviews. He became the spokesman for The National Kidney Foundation and appeared in TV and print ads for several years.

The pace of transplantation and organ donation education picked up in the 1980s. More organs were being transplanted and the need for donation was highlighted throughout the decade by on-going media events and news coverage. President Reagan appealed on television for donors for children awaiting liver transplants (32). Organ donation was in the news, and messages about it were disseminated by many groups. The National Newspaper Index shows a steady increase in the annual number of articles in major papers from two in 1981 to 37 in 1990 (33).

The Federal Task Force on Organ Transplantation, created by the Transplant Act of 1984, specifically reviewed public education initiatives, concluding: "Programs were local, uncoordinated, inconsistent and redundant. Programs lacked specific goals and were not evaluated...Not targeted to minorities...if effective, the ethnic donor profile would more closely resemble the pool of recipients...TV use was uncoordinated and uneven in quality" (34).

Between 1987 and 1989, the American Council on Transplantation analyzed current public education programs under a contract with the Division of Organ Transplantation. Some of its analyses were: "Fears about donating are not adequately addressed... Programs do not convey the message that transplants work... Almost 50 percent of programs do not have an evaluation component... Programs do not meet the specific needs of defined audiences... Programs are generally targeted to the 'general public'... Programs use the same message for several different audiences" (35).

The IOM Study reflects on public attention in the 80s with these conclusions: "The public's willingness to donate organs may be influenced by the newspaper and television publicity that transplantation receives. There may be negative effect of adverse publicity, such as that about anencephalic donation or cross-species transplants. The news value of organ transplantation may also be of limited or declining interest to newspapers and television. These dramatic procedures received substantial television coverage from 1983 through 1986, as public

attention focused on the plight of a small number of individuals, often children... Data developed by the IOM staff suggest that the novelty of organ transplantation may have worn off and that the story may be less newsworthy" (36).

Those three authoritative studies present a discouraging picture of the efficacy of public education in the 80s. This is especially true since spending on public campaigns increased during the same period.

During the 1980s and early 90s, there were many events and projects designed to reach the public with a message about organ donation. They illustrate the best of intentions and uneven results. The plans were mostly made in isolation and carried out with insufficient resources. Groups did all they could, but success was not reflected in the rate of donation. It might be useful to review public education at a time when the field was rapidly changing. These are not an all inclusive history of the decade, but a glimpse of how we tried to reach people because we thought they should support our cause.

One of the first events of the decade was the birth of National Organ and Tissue Donation Awareness Week (37). It began as a single day in 1983 when The National Kidney Foundation brought its Honorary Spokesman, comedian Pat Paulsen, to Washington, D.C. to roam the halls of Congress in search of dignitaries to sign donor cards. Paulsen, known as a perennial Presidential candidate, secured the signatures of several Congressmen and Senators. Modest press coverage resulted, and support was received by the United Steelworkers of America and other groups.

The project was repeated the next year with similar results. Press coverage increased when photos were sent to the Congressmen's home town papers. The following year's ceremony was organized through the American Council on Transplantation and supported by the Dow Chemical Company and their public relations firm (38). Its highlight was the signing of a donor card by Vice President George Bush. The Vice President's participation caused a noticeable increase in publicity as did the services of a professional public relations firm.

The day was expanded into a week and coordinated by ACT for the next several years. Events were sponsored in Washington and included receptions on Capitol Hill and ceremonies featuring recipients and representatives of organizations involved in transplantation. ACT prepared kits with ideas for local activities, which were sold to groups around the country. Many local activities were conducted by ACT member organizations and others. The National Week has decreased in emphasis over the past few years. However, many community projects are still carried out by OPOs and other local groups.

The formation of the ACT was a significant development. ACT grew out of meetings called by Surgeon General C. Everett Koop to determine better means of coordinating activities within the transplant community (39). It was given a substantial boost with seed money from the Dow Chemical Company that facilitated its organization and initial programs (40). ACT described its mission as follows:

- To motivate the public to donate organs and tissues for transplantation;
- To improve donor identification and referral to organ/tissue recovery programs;
- To promote recovery and use of multiple organs and tissues from available donors; and
- To promote equitable distribution of organs and tissues.

"To these ends, the Council provides the ONLY national public policy forum to address and seek consensus on social, psychological, ethical and economic issues involved in organ/tissue recovery and transplantation. This national forum provides the opportunity for all individuals and organizations concerned with organ and tissue transplantation to have an active voice in the discussion and formulation of public policy regarding transplantation" (41).

ACT's early funding and the support of influential members of the transplant community gave it many opportunities to become a focal point in the education effort. It held workshops, produced materials, and facilitated exchange of information at its meetings. It received a government grant to research and compile information on educational programming. The result was publication of the Source Book, a reference guide to educational efforts around the country (42). ACT remained in operation throughout the decade, although it was hampered in later years by inadequate financing. It closed its doors early in 1990.

One personal event made national news when in 1986, United States Senator Jake Garn of Utah donated one of his kidneys to his daughter Susan (43). Senator Garn, the only member of Congress to ride in the space shuttle, was widely recognized for his donation and has served in a number of honorary capacities since the transplant.

A landmark in the public policy history of transplantation was the passage of The Transplant Act of 1984 (44), sponsored by Congressman (now Senator) Al Gore of Tennessee. One stimulus for the law was publicity generated by a physician's plan to set up a kidney brokerage business which would have arranged the buying and selling of kidneys from willing live donors. This received considerable, and usually negative, national press attention, and focused attention on the provision of the Act that would outlaw sale of organs. The Transplant Act also called for the

establishment of a national organ procurement and transplant network (OPTN) to ensure effective organ sharing and the convening of a Task Force to study transplant issues and make recommendations (45).

The organization chosen as the OPTN was the United Network for Organ Sharing (UNOS) headquartered in Richmond, Virginia. UNOS undertook the substantial challenge of devising national sharing policies and procedures and involved the entire transplant community in its deliberations. UNOS has a strong interest in education, including public education, and serves as a major information resource for the media, the public, and the members of the transplant community. It has established a clearinghouse which includes information on national and local educational programs.

UNOS joined a number of other organizations interested in organ donation and public education. The American Association of Critical Care Nurses/NKF resource guide published in 1990 lists 30 different national organizations with roles in educating the public about organ and tissue donation (46).

Since the close of the 80s, public awareness activities have continued with some notable achievements. Among them are the award of a Nobel Prize to two American pioneers in the field of transplantation, Dr. Joseph Murray of Boston and Dr. E. Donnall Thomas of Seattle (47). The U.S. Transplant Games were held in Indianapolis in October 1990 and featured athletic competition by 400 recipients of vital organ transplants (48). A White House reception was hosted by First Lady Barbara Bush in April 1991 to salute the entire transplant community and its work (49). And this Surgeon General's Workshop brings focus to the responsibility we have to search for new and better solutions.

Traditional Primary Sources of Public Education in Organ Donation

For most people, transplantation is not a part of their own personal world. It is a rather exotic medical treatment involving other people. The media is the basic source of experience with transplantation and organ donation for the majority of Americans.

News coverage of transplantation has been consistently available when developments warranted. When the story was dramatic, like appeals for children needing liver transplants, the coverage was extensive. The first heart transplant (50), the conception of a child to be a bone marrow donor (51), the donation of a baboon heart (52), the living donation of a part of a liver (53), the donation of a kidney by a United States Senator all were reported (54). Also, bad publicity can be extensive. When a physician wants to sell kidneys (55); when foreign nationals are transplanted ahead of Americans (56); when blacks wait twice as long for a

transplant, it's news (57). Table 1 shows that throughout the 1980s, coverage in the country's leading newspapers was growing and fairly frequent (58).

The National Kidney Foundation's clipping service estimates that over 50 newspaper articles on organ donation appear each week in the United States (59). Table 2 shows the number of general interest magazine articles published annually in recent years (60). Local events, from dedication of new hospital facilities to mayors signing donor cards, make the news. Individual recipients also stimulate coverage, from Michelle Kline, a transplant recipient who was Miss Pennsylvania, to the youngest, or smallest, or thousandth recipient.

Television is the most frequently recommended medium for public awareness or education messages, and was so cited by the Federal Task Force on Transplantation, the IOM Study, the Oberley study, and the ACT Report (61). In today's society, television is a dominant force in determining public sentiment. It also is a highly structured business and contrary to the impression of many people, is under no obligation to run our public service announcements or devote time to our cause. It is required to broadcast "in the public interest" but it has a lot of latitude in defining that term. That means, organ donation must compete with every other good cause for media attention.

Early in 1991, several network TV series inaccurately depicted the organ donation and transplantation process. They addressed some of the worst fears and barriers to donation the polls have identified (62). On *L.A. Law*, a person needed a kidney transplant and the lawyers arranged to buy the organ from a woman who agreed to claim to be a relative (63). On *Knot's Landing*, a main character needed a liver transplant and a relative bribed the hospital staff to give him a donated liver rather than to the first recipient in line, who consequently died (64). The most outlandish story was on a segment of *Law and Order*, where a surgeon was paid a lot of money to kidnap a person and remove his kidney, leaving him to die, and then transplanting the organ into a rich patient (65). Even the sitcom *Doogie Howser, M.D.*, had a segment in which the decision about donating organs was presented in a rather coercive way (66).

More people saw these four shows than any of the television coverage of the shortage of donors. There were many angry phone calls and letters after the shows aired. Still, the concept of organ donation was put before millions of Americans. Is this publicity necessarily bad? It's beyond the scope of this paper to explore that question. However, these fictional portrayals may have started more family discussions than all the public service announcements broadcast this year.

Public service announcements (PSAs) are an integral part of a total media campaign. They are used by local stations, cable systems, cable channels and the

broadcast networks. They are the mainstay of charities and causes and are everyone's first thought in educating the public. Studies show they can be effective (67).

A 1991 study, "Measuring Advertising Effectiveness", was conducted by the Advertising Research Foundation in cooperation with the Ad Council and the American Cancer Society (ACS) (68). The study took 2 years and cost over \$1 million. It measured the public impact of one PSA in four markets: Eau Claire, Wisconsin; Marion, Ohio; Grand Junction, Colorado; and Pittsfield, Massachusetts. The PSA was devoted to awareness of colon cancer, and it measured response by assessing actions related to consulting a physician and getting tested. The study found, "...the use of public service advertising alone not only increased awareness, but also reinforced people's beliefs, fostered their intent to act and inspired potentially life-saving action" (69).

The study used only one ACS TV spot which was repeated frequently. An assessment was made of the number of people who took some action after seeing it. It utilized purchased air time in which the PSAs were substituted for regular commercials. This allowed the study to target the audience it wanted to reach. That time used came to over \$25 million. The campaign was successful in the opinion of the study's authors. A large number of people, especially men whom they had specifically targeted, saw their doctor and were tested.

The study proved that a public service announcement used consistently and frequently for a long period can provoke action leading to better health. However, the methodology was totally unrepresentative of a typical public service campaign. Thus, the results are terribly misleading. In the real world, the effectiveness of this study could never be duplicated.

The study states, "To control media placement, they relied on three national advertisers...to donate some of their paid advertising time for running this campaign." That simply is not going to occur for us on any meaningful scale. The study continues "...a concerted effort was made to target men by placing more PSAs than usual in sports, prime-time and early news programming" (70). Such accessibility is not possible when PSAs compete for donated air time. Organ donation might also reach more men if corporations such as Proctor & Gamble, Gillette and General Motors were to purchase \$25 million worth of time for it. That is not realistic.

The study summarizes, "If the major goal of a public service advertising campaign is to build awareness, this study showed that an average level of advertising can accomplish this goal. It also showed that consistency and targeted media placement are important in increasing awareness. The longer a public service

campaign runs, the more awareness can be expected to increase. The more targeted the media placement, the more awareness will increase among the target audience" (71).

The main premise of the study is stated as follows, "...consistency and targeted media placement are critical in maximizing the effectiveness of public service advertising." The study proves that statement. However, we cannot duplicate the experience reported in that study. We have to deal with the real world of donated TV time (72).

The effectiveness of a public service campaign can be increased by the participation of the Ad Council (73). This coordinating group is very important in securing donated creative services from professionals and critical in getting placement from the networks and, to a lesser extent, local stations. The Ad Council operates today under new rules, adopting causes rather than specific organizations. It helps coalitions develop funding sources and secure the best creative talent (74). The Ad Council seal confirms that a spot has been competently done, thoroughly researched, and deserves premium placement.

The study by the Advertising Research Council describes the typical Ad Council Project: "In 1989, total donated media support for the more than 30 Ad Council campaigns ranged from a low of \$6 million to a high of \$100 million. Fully three-quarters of these campaigns fell within the \$6 to \$30 million range, which means that the value of donated media averaged approximately \$18.2 million a year for each campaign" (75).

William Clotworthy, former Public Service Director for the NBC Television Network, devotes 50 percent of his available time to Ad Council or Media Partnership (the recent campaign on drug abuse), 10 percent to NBC's own public service program, and the remaining 40 percent to all other causes (76). Harvey Dzodin, Vice President of Commercial Clearance for the ABC Television Network, reports that only Ad Council or Media Partnership spots go over the network in non-coverable (local stations can't substitute local spots or commercials) time (77). These are two of the "gatekeepers" who actually decide what television does with our messages.

Another common practice is to use celebrities to convey messages. A large number of celebrities have been involved in reaching the public about organ donation, including Bill Cosby, Delta Burke, Whoopie Goldberg, Gary Coleman, Pat Paulsen, Pernell Roberts, Bea Arthur, Carl Lewis, Sugar Ray Leonard, and others. The National Kidney Foundation conducted a nationwide mail survey of 1100 television public service directors in April 1991 (284 responses were tallied). They were asked to rate the importance of various factors in devoting air time to a campaign. Only 33 percent rated the appearance of a national celebrity very

important in their decision making; 27 percent rated it not important. In fact, local celebrities rated higher with 41 percent saying they were very important and 18 percent saying they were not important (see figure 8) (78). Celebrities do call attention to a cause or an issue, however they increase the cost of a campaign and the production requirements.

Much effective communication happens person-to-person. Such avenues are typically part of a balanced educational campaign. By their nature, they are local activities and are the responsibility of local transplant community members. These tactics run the gamut from health fairs and donor signing events to a concerted effort to speak to every service club in the area once a year. Service clubs are frequently good prospects for co-sponsorship of a donor card campaign. The Lions Clubs have led the way for many years with their commitment to the Eye Bank program. National organizations frequently develop materials which can be used by local representatives in meeting the public and disseminating information. Religious institutions, places of worship, community organizations and schools all offer opportunities for contact with the public. They are places where Americans get information upon which they build their attitudes.

Another important venue for dissemination of information is drivers' license bureaus (79). Most states allow a notation on drivers' licenses that the holder wishes to donate organs and tissues. Some have an actual donor card on the license. When people get or renew a license, there is a major opportunity for education. Only a few States require that the question about organ donation be asked and answered. Most leave it up to the individuals involved to notice that the license can be a donor card. In several areas, organizations have made a major push to educate license examination personnel and to create a display of information in each station. In Maine a major campaign has been launched with the Lions Clubs and the National Kidney Foundation of Maine. The District of Columbia Organ Donation Program also had an excellent relationship with drivers' license examiners. They have a presence in every drivers' license bureau which gets the attention of everyone who comes in.

The opportunity is especially compelling when a young person gets their first license. If they say yes the first time, it may become a life-long habit. It is also significant that people under 18, as first-time drivers frequently are, need a parent's signature on the donor card. That creates a family discussion.

An important aspect of translating opportunities for reaching people into actual changes in attitude, is to provide a mechanism for them to get further information or have questions answered. TV spots are frequently required to carry a phone number for further information. Posters and other signs, direct mail pieces and

displays can feature a number or an opportunity for follow-up. Within a community there are usually several sources of such information. Agreement among the organizations may make the access consistent and reliable.

Attitudes and Barriers Which Impact on Organ Donation Public Education

The transplant community has identified attitudes the public may have which negatively impact their support for donating organs. Typical barriers are:

- Distrust of the medical care system
- Discomfort with the topic of death
- Discomfort with the topic of organ donation (80).

The community is also familiar with the characteristics of those who are likely, and unlikely, to donate. Oberley reviews the subject: "Research has generated a very clear and consistent demographic picture of persons most likely to express willingness to donate their organs after death. Without exception, studies have described the likely donor as white, younger rather than older, having more education and enjoying a relatively greater yearly income (Battelle, 1985; Gallup, 1987; Perryman, 1990). Conversely, the same studies have described those least likely to express willingness to donate as being black, over 45-55 years of age, with low income and little education" (81).

One of the comments from the Surgeon General's Advisory Workshop Committee sums up another major barrier to successful organ donation: "A primary reason for refusing to donate is, 'we've never discussed it and we don't want to think about it now'" (82).

Another barrier is the concept of "brain death" which the general public does not understand. Many in the transplant field recommend abandoning the term, choosing to talk about death without the qualifier. It is a confusing term. A 1985 Gallup Poll showed: "Less than half (45 percent) believe correctly that a person must only be considered clinically brain dead in order to have that person's organs donated" (83).

Another comment from the Workshop Advisory Committee: "A major problem in promoting organ donation is the fact that it deals with the subject of death and our society does not discuss death" (84).

Barriers to organ donation include the disparity between blacks and whites in awareness and willingness to donate. In 1986, Jeff Prottas stated, "On each

attitude question Black Americans are less supportive and aware of organ donation than are Whites." Prottas continues, "In our society there is a strong connection between a person's race and the ... education he or she has received. For this reason, it is possible that the strong effect of race on attitudes may be misleading; it may be that it is really a person's educational level that determines attitudes not his race." However, Prottas goes on to state, "...in each case the effect of the race variable is stronger than that of the education variable...These findings imply that if we compared a group of people with the same amount of education we would still find significant differences by race" (85).

The Institute of Medicine summarizes the problem: "Black individuals account for 28 percent of the incident ESRD patient population, even though they represent only 12 percent of the U.S. population; their incidence of renal failure is nearly four times that of whites. Regarding kidney transplantation, black ESRD patients represent about 30 percent of those on waiting lists but wait nearly twice as long to obtain a kidney as do whites; they receive over 22 percent of cadaver transplants and 12 percent of Living Related Donor transplants. They donate slightly over 8 percent of cadaver organs" (86).

All these barriers work against the acceptance of our educational messages. They are attitudes we need to change and fears we need to address. It is a formidable task to create a single educational campaign which deals successfully with all these factors. The basic response we have supported has been the concept of "altruism," that organ donation is "right" and that people should support organ donation and give permission when asked. We have concentrated on message content, believing that the public ought to pay attention because it is important. However, organ donation is not very important to the public. Television public service directors are excellent barometers of public issues in their community. In the NKF survey, they were asked to rate the importance of organ donation relative to the issues (figure 5). The largest response was "5". AIDS came in number one.

Organ donation also is not as visible as we think and certainly not as visible as we hope it can become. Seventy-five percent of the public service directors rated the visibility of organ donation in their communities a "5" or below (figure 4) on a scale of one to 10 (87).

The NKF conducted a more intensive telephone survey in 14 communities seeking the opinion of the public service directors, the local OPOs, and the local NKF Affiliates. In that study (figure 1), 86 percent of OPOs thought organ donation was greater than "5", as did 60 percent of NKF Affiliates, but only 34 percent of the public service directors thought it was greater than "5" (88).

Public service directors have a good sense of the importance and visibility of public issues in their community. We must compete for their attention. A study by

Needham, Porter, Novelli in 1985 for the National Heart, Lung and Blood Institute indicated that public service directors receive 15 public service spots a day. They have 175 different spots in their rotation at all times (89).

We cannot control access, we can only compete effectively for it. One of the means of competing most effectively is to know where the control actually is and how best to influence it. That rests with the group referred to as "gatekeepers".

"Gatekeepers" for Public Education Campaigns

"Gatekeepers" are people who control access to the mediums through which we seek to reach the public. Every medium has its gatekeepers. Every group of gatekeepers has a set of rules and regulations for access. They also have ideas and preconceptions about what interests and benefits their public.

Schools have superintendents and boards of education; newspapers have editors; service clubs have program chairmen; health fairs have committees; drivers' license bureaus have supervisors and television has public service directors. All of these people are in positions to decide whether or not our messages are used. We cannot reach an audience without going through these people. Yet, organizations which have a mission of educating the public usually do not find out what these people think before they create their campaigns. For instance, not one organization involved in producing television public service spots about organ donation is a member of the National Broadcast Association for Community Affairs (90).

Since television is so vital to the organ donation public education effort, the results of the NKF survey of television station public service directors (mentioned earlier) can be informative. In addition to specific questions, the respondents were also asked for advice (appendix 1) and several responded on the need to listen to them, to public service directors. For example:

- "Get to know the public service director and station policies on PSA placement."
- "Make a personal contact with the Program Director and person responsible for PSAs and get to know them. Find out what they want and need and work with them."
- "MORE organizations should do research so they provide airable spots!!"(91)

The most important survey result was the overwhelming sentiment that television campaigns should be local: 92 percent of the public service directors responding said the "local angle" of a spot was the most important, or very important factor in their decision to allocate air time. Only 18 percent of the respondents thought a

nationally produced spot was the most important, or very important factor in their decisions about air time (figure 8) (92).

When evaluating available spots, respondents said they base their decisions on the local aspects of the campaign and the PSA itself. It also helps to have the spots delivered by a local representative: 54 percent of the respondents were more likely to use a spot if it was distributed by hand or by a local representative of the organization. Only 19 percent said they were more likely to use a spot delivered by mail (figure 6). Some of the comments make this point very strongly:

- "Our license and mission is to serve our local audience in terms that relate to their lives and needs."
- "Testimonials from recognizable, hopefully local, recipients of transplants would play well here."
- "Local angle and local contact numbers are very important to my station."
- "Try to localize....This way the frequency of air time increases." (93)

The results of this survey are entirely consistent with the survey of 30 public service directors done in 1985 by Needham, Porter, Novelli which found: "When participants were asked to specify what criteria they use in deciding whether or not to air a PSA, comments by nearly three-quarters of the overall sample related to local impact." The study said that play on a station can be increased by: "producing a greater number of locally oriented spots containing a reference to where people can get more information, sending spots with local tags...." In general, the 1985 survey concludes: "Seven out of ten respondents say that local contact influences them either to a moderate or great degree" (94).

National organizations may place too great an emphasis on network television's participation in campaigns. The networks have their own gatekeepers, rules, and practices which work to the disadvantage of issues like organ donation. For example, local stations can "cover" a network public service spot with a local spot or a local commercial (95).

There are spots which are placed in "non-coverable" slots, broadcast over every station on the network. However, access to those slots is extremely limited. ABC network limits such spots to Media Partnership or Ad Council campaigns, and use 10 to 15 each week. All others must compete for the 20 to 30 slots available, all of which are "coverable" (96). It is possible for local stations to pick up network spots. They can use them as they are broadcast, or get them "off line" from a network feed of currently in-use spots. However, the survey showed that 83

percent of local public service directors "seldom" or "never" pick up network spots, and only 3 percent of major market public service directors "frequently" pick up network spots (figure 3) (97).

These results clearly suggest what any cause-based group must do to reach intended audiences. The gatekeepers are in charge. Getting to know them and working with them is vital. The best message in the world, with the best content and the best production, will be received only if the gatekeepers allow it.

National and Local Public Education Campaigns on Organ Donation

The national organizations which produce public education campaigns on organ donation must maintain a spirit of cooperation. An exchange of information on plans and campaigns should benefit each organization without compromising any group's ability to meet their own internal needs. For instance, each organization will have a unique set of needs in addition to the goal of increasing organ donation. Some of those needs are:

- to create public awareness of the organization and its value to the community;
- to inspire public support, including financial support;
- to establish a programming presence, so the public understands what funds accomplish through the organization;
- to inspire and motivate the organization's own volunteer corps, or prominent supporters;
- to use resources available to it; such as an offer of participation from a celebrity;
- to demonstrate an ability to produce materials of high quality which impress volunteers and supporters.

Secondary goals (after the primary goal of increasing organ donation) are perfectly legitimate and often complement the mission of the education campaign. It is impossible for an organization to ignore all of these factors in planning a campaign. The problem arises when these things create pressure on the campaign, which may result in higher costs, production problems, or a lack of clarity in the message. This can compromise effectiveness of a campaign. However, when these needs are acknowledged and dealt with honestly, the results of a campaign can still be good.

Another common problem in campaign creation is the tendency to over-produce materials, especially TV spots. High quality does not necessarily mean expensive or glitzy. When creativity is allowed to charge ahead unrestrained, production can get out of hand very rapidly. Four color printing, glossy paper, celebrity studded

TV spots, elaborate sets, and fancy video graphics, all make things impressive. However, the real utility of these tactics must be measured against the goal.

Again, our advice on television comes from the public service directors who were asked to rate factors in the effectiveness of TV spots. 49 percent said emotion was most effective. 44 percent said education was most effective. Their comments advise staying away from the fringes of advertising. Shock was listed as only 10 percent effective (figure 8). Some of their comments were:

- "Don't rely on celebrity - - confront the basic issue head-on."
- "Don't be clever - - remember that PSAs are aired over and over. Don't be melodramatic..."
- "That the announcement be very simple, clear, easy to understand."
- "Simplicity is best."(98)

One of the principal responsibilities of the national campaign planning process must be the absolute commitment to accuracy. The television networks demand that complete justification accompany the script of any TV spot they are asked to run. All claims have to be substantiated. The networks will reject a spot which cannot fully explain why it states what it does. This is especially true for the national campaign which will be implemented locally.

Another ingredient of any campaign is evaluation. In the survey of 14 area OPOs and NKF Affiliates, the respondents were asked if they routinely evaluated the effectiveness of their campaigns. 69 percent of the OPOs said yes. 54 percent of the NKF Affiliates said yes (figure 2) (99). Evaluation is harder on a national basis. However, the evaluation that matters most is the rate of organ donation. 1990 results notwithstanding, we haven't been doing very well in the past few years.

Consistency is another issue which gets considerable attention from organizations trying to reach the public about a single issue. 64 percent of the OPOs in the survey reported that they make an effort to be consistent within their community. 54 percent of NKF Affiliates reported a similar effort (figure 2) (100). Nationally there is almost no consistency and no formal mechanism at present to strive toward. Since the evidence presented here suggests that local campaigns are more utilized (certainly on TV) the need for locally consistent messages is reinforced.

One of the most repeated criticisms of past efforts in public education on organ donation is the lack of message targeting (101). This is very hard to remedy. Mass appeals can't be segmented by audience under our circumstances. We can't control our placement on television. Since we rely on free public service time, the only group we can be sure to target are insomniacs (since late at night is a common time slot for public service). One mass campaign can't target minorities,

or women, or young people. If the desire is to specifically target such audiences, the evidence tells us that it will be necessary to design unique campaigns for them, and deal with the gatekeepers in a specific way.

Mass campaigns, especially on television, reach very large numbers. They are designed to appeal to the population in general. Their audience is the 250,000,000 people who live in the United States. If that represents 75 to 80 million families, our statistics indicate that less than 1 percent of those families will be confronted with an actual organ donation situation next year (102). So, 99 percent of the people we are targeting for our mass media campaign will not directly be in a position to help us meet our goal (increasing the number of donations).

Allocation of scarce resources is one of the decision making processes the transplant community goes through every day. No organization has enough money, time, or volunteers to do everything necessary to dramatically raise the rate of donation. Therefore, we have to make choices. The types of public education campaigns we do is one choice. Allocation of resources between public education and professional education is another. Some of the information examined in this paper may prove helpful as we face those choices.

Howard Nathan states: "Educational efforts directed toward the general population with an accent on minority groups are capable of producing a modest increase in actual donors [emphasis added]. Educational programs aimed at increasing the organ donor pool should design methods to identify these individuals (missed donors)....improvement in donor recognition...could be achieved by creating focused educational programs targeted toward health-care professionals in hospitals identified with the largest 'donor gaps'" (103).

The Institute of Medicine Study also focuses on the dynamic in the hospital when the actual determination of donation is made. It states: "Cadaver donation involves a complex process between the attending physicians and nurses caring for the recently deceased potential donor, the organ procurement professionals and the family of the deceased. The initial encounter with the family is critical. It is most effective when made by professionals who show respect to the family and communicate a sensitivity that acknowledges their grief. However, if the requestor is uncomfortable, or lacks answers to important questions, the result is often refusal" (104).

Again, Howard Nathan points out that in Pennsylvania during his study, there were 147 actual donors, 91 refusals and 114 to 215 families who were never asked (105). If the real determination of success for organ donation education efforts is in the number of organs donated, the problem is apparent in that statistic. Polls

showing general public awareness deal with a universe, 99 percent of which will not be in a position to decide about organ donation.

The Institute of Medicine studied only the renal program. However, it reflects the entire field of transplantation when it states: "The committee wishes to underline the urgency of increasing the organ donor supply as the central issue in making kidney transplantation available to increasing numbers of ESRD patients. Public and professional education, recommended consistently over the years, should be continued, but working assumptions should be re-examined and efforts possibly re-focused and the effects on increasing the availability of organs should be monitored closely" (106).

Conclusions

A review of public education in organ and tissue donation, and the concepts described in this paper, lead to the following conclusions about the transplant community's need for an effective relationship with the American public.

1) The goal of public education in organ and tissue donation should be:

To maintain a level of public awareness of organ and tissue donation which will favorably dispose families toward donation if they are ever asked to grant permission.

The elements of the "level of awareness" which will pre-dispose families are a sense that:

- a) Transplantation is "good".
- b) Organ donation is the "right" thing to do.
- c) When a person dies "senselessly", the only "good" possible is organ donation.
- d) The person who died, a "good" person, would have wanted his or her family to do the "right" thing.

The most important factor in predisposing families toward donation is knowledge that it is what their loved one would have wanted (107). The best source of that knowledge is a family discussion of organ donation and transplantation.

2) We must realize that organ donation is a unique health education concept. Some of the factors which make it different are:

- a) It is not something you can do yourself.

- b) It is not something that benefits you at all.
- c) You cannot cause it to happen.
- d) It depends absolutely on someone else doing something.
- e) It is extremely unlikely.
- f) It only occurs after you are dead.

Our educational planning should include these realities.

3) We should set much more realistic goals for public education based on the following ideas:

- a) In organ donation, public education is a supportive, not a primary activity.
- b) 94 percent awareness means the main job is maintenance.
- c) We shouldn't strive for total understanding of the concepts because they are too:
 - i) complicated
 - ii) negative
 - iii) easily misinterpreted
- d) We should stick to basic, easily assimilated, simple themes and repeat them without the details.

4) We must invest our money and effort carefully, thoughtfully, and honestly. We should always know why we are doing things and what we expect to accomplish. To the extent we want to focus solely on increasing organ donation, these concepts should be considered:

- a) The resource investment mix between public and professional education should be carefully analyzed based on the likelihood of positive results.
- b) National television campaigns are very expensive and not likely to be cost effective or produce significant results.

5) Local public education campaigns and activities are much more important than national ones and will bring better results.

- a) The vast majority of educational message "gatekeepers" are local.
- b) These "gatekeepers" overwhelmingly advocate messages that have a local angle and local focus for action.
- c) The national role should concentrate on creating model materials and concepts for local adaptation and use.

- d) Local campaigns should be broadly based using a cooperative approach among the local transplant groups.
- e) Consistency within a community is important; consistency with the rest of the country is less so.

Television is usually our first thought when we want to reach the nation. However, the access to national television is extremely limited. There isn't much network time, most of that time is committed to a few select issues, and stations cover national spots with local ones anyway. To communicate with the American people through public service announcements, we have to concentrate on working with local TV stations.

6) Public education encompasses a large variety of tactics. It is not limited to mass media.

- a) Media campaigns should be supported by local community involvement. TV Public Service Directors advocate events and always want further information resources to back up spots they play. They even suggest asking them to co-sponsor events.
- b) Health fairs, donor card signings, speakers bureau, work-site campaigns, and countless other tactics can be the most effective means of reaching people.
- c) Cooperation and efforts toward a consistent message are very important on the local level. Organizations can share the planning and cost.
- d) There should be standard ways for the public to request further information or contact with knowledgeable representatives of organ donation.

Hands-on public contact is time consuming but it reaches people directly and involves them in thinking or talking about organ donation. Speakers bureaus and health fairs reach relatively few people yet they cause people to focus on, and possibly to talk to their family about, organ donation.

7) We should spend more time realistically evaluating our educational efforts. Each campaign objective should be examined carefully:

- a) Though the primary goal of education is raising the rate of donation, other goals such as the organization's need for recognition are complementary and perfectly reasonable.
- b) Secondary goals are valid; however, they shouldn't predominate.

- c) Secondary goals sometimes raise the cost and guide the creative process in campaigns.

It is reasonable for an organization to expect its public image to be enhanced by effective educational campaigns and its own volunteers and supporters to be inspired by its campaigns. However, accomplishing those secondary goals doesn't mean that the mission of increasing organ donation has been advanced.

8) Donor cards, a long-time tool of public education programs, should continue to be distributed widely. Though signing a donor card is part of our message to the public, they are primarily a catalyst for family discussion.

- a) The fact that donor cards are legal documents should be de-emphasized. Their use is in awareness, not in recovering organs legally.
- b) We should focus on who witnesses a donor card signing, and urge that it be a family member.
- c) Donor cards, or notations on drivers' licenses are very important opportunities to reach the public.
 - i) We should make drivers license examination locations part of our public education program.
 - ii) We should educate young people when they obtain their first license.

9) We should realistically analyze the audiences we seek to reach with our educational messages. Our mission is not to educate the American people. Our mission is to increase organ donation. Therefore,

- a) It is reasonable to concentrate first on the people with whom we have the greatest chance for success: the people most likely to donate.
- b) We want to reach the 12,000 or so families who will face, or could face, a decision about organ donation next year. We don't know who they are, but thinking about them might help us do a more effective job of education.
- c) The more we know about those 12,000 families, including projection about which ones are likely to be asked and which ones are likely to say yes, could be very valuable.

10) We need to target some audiences even though we know they are less likely to donate today. This is especially true of African Americans. Their need for

organs is clear and so is the need for them to donate. But, planning such campaigns must include some special elements:

- a) Campaigns targeted at minority audiences are harder.
- b) They are much less cost-effective.
- c) The primarily White leadership of the transplant community needs additional help, advice and participation, before it can produce effective targeted campaigns.
- d) Adequate resources must be devoted to such a targeted campaign. It cannot be a slight variation of some other effort. It is worse to do an inadequately planned or executed campaign than to do nothing.
- e) The results of targeted campaigns should be evaluated on their own criteria.

All educational planning must take into account the special circumstances of the minority community need for more organ donation.

11) We must focus on realistic expectations. We should be creative, enthusiastic, optimistic, and persistent, but our sights should be firmly set on what is attainable.

- a) To most people, our issue is a "5". AIDS, drug abuse, education, the homeless, jobs, crime are all more important to somebody and some are more important to everybody. The public can focus on only a few "10's" and organ donation isn't going to be one.
- b) Networks devote their available public service time first to the Media Partnership, the Ad Council, their own "house" campaigns and then to everybody else.
- c) Effectiveness depends totally on utilization and utilization is most often out of our control. We can target an audience, but, if we can't control placement, we can't expect to reach the targets.
- d) We should resist the temptation to buy television time or recruit someone to buy it for us. A paid campaign would be extremely expensive, could not be sustained over a long period of time, and it would destroy our ability to get free public service time in the future.

- e) We must educate the "gatekeepers" about whom we know very little. They decide what reaches their audience.

12) An intensive study of the current donor pool should be undertaken. Information about today's donors, potential donors, and unrecognized donors can help us anticipate tomorrow's needs and opportunities.

- a) Which families get asked about donation today and which do not?
- b) Which families say yes to donation and which say no?
- c) Of the families not asked, are there some likely to say yes and some likely to say no?
- d) Which families are most able to increase the number of organs donated? Can we target educational activities at them?

13) The next public opinion poll done by the transplant community should examine the impact of inaccurate or bad publicity on public attitudes toward organ donation. In 1991, organ donation was falsely portrayed in several popular television series. What really resulted from that?:

- a) Is bad fiction taken for bad fact?
- b) Can even outlandish presentations stimulate discussion and interest in organ donation?
- c) How can the transplant community use such portrayals, seen by millions, as a catalyst for positive results?
- d) How should we respond when these things happen?

A 1985 Gallup Poll showed that 92 percent of the people who were aware of transplants heard about them on television. If such dramatizations are going to occur, it might be possible to turn them to our advantage.

14) A national public education consortium is needed. Exchange of information on plans and ideas would be very valuable to every organization which invests time and money in organ donation education. The consortium should be a clearinghouse created solely for the exchange of information:

- a) It should not conduct its own programs.
- b) It should not raise money.
- c) Its administrative expenses should be shared by the member organizations.

- d) It should concentrate on how to facilitate better educational campaigns on the local level throughout the country.
- e) It should provide a regular forum for discussion of member's initiatives.

The UNOS clearinghouse could easily be expanded to serve as the focal point for this consortium.

15) The Federal Government should not play a visible role in the public's awareness of organ and tissue donation. The transplant community understands and appreciates the vital role played by the government but it may not be productive to associate the government with organ donation in the public's mind.

- a) Among some, a distrust of the medical establishment is a major barrier to accepting organ donation. If we add distrust of the government to that equation, the situation could be worse.
- b) The government will have a distinct role in furthering organ donation education; however, it should be a supportive role acting through other organizations.
- c) The visibility of organ donation education should remain with the private sector even when actual programs are funded by the government.
- d) Any perception that the government is monitoring who is willing to be a donor, or who is or is not donating is a very strong negative.

In this sensitive personal dynamic, the role of the government has to be circumspect. This is not a criticism of the many ways government facilitates organ donation. It just has to be careful in the fragile relationship between organ donation and the public.

16) Organ donation has always rested on a foundation of pure altruism. The "Gift of Life" has always been a freely given gift. The continuing shortage, however, has led some people to begin considering non-traditional approaches. Our educational campaigns and efforts should not be modified now. However, if we consider non-traditional approaches, we should evaluate them from a public reaction perspective.

- a) A study should be undertaken of the public reaction to concepts such as financial incentives for donation, maintaining a registry of potential donors, requiring a decision about organ donation at some point (drivers'

- licensing or hospital admission) and presumed consent.
- b) Full debate and discussion should be encouraged on all these non-traditional approaches before they are tried.
 - c) Pilot trials of these approaches should be conducted to test their effectiveness and acceptance by the public.
 - d) Relevant laws and regulations should be modified so that the trials can be conducted thoroughly.
 - e) Intensive effort should go into the public relations aspects of each step in this process so that decisions are made with the attitudes of the public as clearly in mind as possible.

SUGGESTED RECOMMENDATIONS FOR THE SURGEON GENERAL

- 1) A national consortium of organizations doing organ donation public education programs should be formed under the auspices of the United Network for Organ Sharing.
- 2) The Ad Council should be asked to adopt organ donation as a major campaign.
- 3) A national television campaign should not be developed unless organ donation is adopted by the Ad Council and funding is available through its sources.
- 4) The Congress should authorize the Department of Health and Human Services (DHHS) to conduct pilot tests of non-traditional approaches including financial incentives.
- 5) The Division of Organ Transplantation (DOT) should make "seed money" grants available for the formation of local coordinating groups.
- 6) The DOT should fund in-depth studies of the public's attitudes toward non-traditional methods of facilitating organ donation.
- 7) The DOT should fund demonstration projects on educational programs targeted at minority audiences.
- 8) The DOT should fund an in-depth study of the current donor pool to project similarities and differences among the four groups of families (asked and said yes, asked and said no, weren't asked and would have said yes, and weren't asked and would have said no).
- 9) DHHS should indicate the special circumstance of organ transplantation, that donated organs are required before medical treatment is possible, and therefore

creates a unique need to include public attitudes in planning government sponsored medical care initiatives.

10) DHHS should form an inter-agency group to consolidate information on transplantation and organ donation programs of various government agencies.

11) That inter-agency coordinating group should promote the need for a public awareness focus in the scientific and public health work being done in transplantation.

12) The Secretary of DHHS and The Surgeon General should continue their leadership in regard to this issue and stimulate greater attention to it within the government.

13) The Surgeon General should sponsor a follow-up workshop in 2 years to evaluate progress made on implementing the recommendations coming from this workshop.

Appendix I

The National Kidney Foundation, Inc. Survey of Television "Gatekeepers" April 1991

SURVEY COMMENTS

Question: What advice would you give to organizations planning to produce television public service announcements on organ donation?

FORMAT

- Generic without time or date. Put all time lengths (to fill variety of station formats) on one reel, that is 10, 15, 20, 30, and 60 second formats. Do variations so several spots can rotate without spot getting "tired".
- Supply varying lengths of spots but not several 30 second spots with different themes.
- Be sure to produce 60 and 20 seconds as well as 30 seconds.
- Often P.S. Directors are limited by how many spots of a certain length are available in their PSA rotation. You increase your chances for air time by giving the P.S. Director options.
- At our station there is less competition for air time for PSAs other than 30 second. Short spots fit better--20, 15, even 10 seconds.
- Guidelines for PSA's from WTXF-FOX 29:** We air 10, 20, 30 and 60 second PSAs in accordance with daily availabilities. For consideration: Send 1" videotape reel accompanied by cover letter, IRS non-profit tax-exempt number statement, scripts/storyboards, and background information. Include full name and address of organization and contact person. WTXF-TV must have this information to process and to issue monthly performance reports. Don't send slides. Allow for a 6-week processing period. All tapes are screened for content and technical. If selected, the public service announcement airs for 6-months or until the specified kill date. A monthly performance report

will be sent to organization providing contact information. Please enclose a self-addressed stamped envelope.

-Offer 1-3 different lengths and make the spot so it will hold the interest of viewers.

APPROACH

-Keep it simple-provide a call to action for your viewer. Don't try to give too much information in :30. More organizations should do research so they provide airable spots!!

-Include a racial balance, i.e., it affects all races and socio-economic backgrounds. There's a concern for lack of minority donors.

-Sensitive subject; personal...some might think talking or "body parts" too personal. A sensitive subject needing a sensitive approach.

-Spots must be generic, cannot ask for specific donations.

-Make a generic spot with no end date.

-Make good spots but don't try to get too technical as people don't understand technical side of most things. Also make spots kind of simple and not too deep.

-Get creative and make sure you have universal appeal (to all age groups) or produce different spots aimed at different demographics. Include local phone number on spot, if available.

-Be creative with your presentation of the message. Be careful to make the spot "work" in all parts of the country (urban/rural). Make part of the spot a "call to action" to get the viewer to do something, or simply to be more aware.

-Be sure to appeal to the minority audience.

-Keep it simple so it can have a long play...repetition is your best promotional weapon when time is needed for people to decide to join the effort.

-Make sure the spots are well produced and don't use "talking heads", there is nothing more boring than a spokesperson on camera talking for several seconds.

-Offer the viewer a sense of revelation while communicating the information! Show real life situations/happy endings?/not happy endings? More information needed for general public to get comfortable with idea.

-Although I indicated that education signals effectiveness, keep in mind that education is only possible when you have the public's attention. How? Emotional, shocking, humor, etc.

-Include the following: emotional (touching, tear jerker, cute, shocking, etc.) music that demands your attention and holds it, fast moving - all information quick and to the point. 30 second spots are best.

-I would present it as real and graphic as could be done, along with someone who is in the public eye.

-I have done a half-hour program on organ donation and am intellectually convinced myself. I think the BIG problem is that of describing what DEAD is.. some organs (all?) may be harvested prior to what people believe DEAD to be! This is a big problem. The organ donation program really must depend on an enlightened, courageous and informed person. Even the best of us wince a bit!

-Produce it in a way where it is informative and educational yet entertaining. Too often I find PSA dull or slow-paced which entices viewers to switch channels. Good video and music helps.

-Show how simple it is to be an organ donor. Explain the steps needed to be an organ donor. Education on how to be a donor.

MESSAGE

-Testimonials from recognizable, hopefully local recipients of organ transplants would play well here. Recipients expressing the quality of life slant. Also, testimonials from family members of organ donors. Again, using local people.

-Testimonials by organ donor receivers; how the organ donation saved their lives, for example.

-Show more than a "talking head". Give good reasons why the general public should support this effort.

- Use the Human Interest ("This could happen to you/someone you love" angle.)
- Address the (hopefully false) contention that families of organ donors receive unanticipated bills to cover expense of removing, transportation and processing donated organs - bills which previously were assumed to have been the responsibility of the donee.
- Use faces - maybe a child's true story about receiving an organ so he/she could live.
- Find local recipients willing to be interviewed. They're much more interesting than "celebrities". When there's a local story call the local news media that day.
- Let people know how vital it can be in saving a person's life, and how easy it's to agree to be an organ donor on your driver's license. I would probably provide more time for kidney disease PSAs if the PSA demonstrated just how many people suffer from this problem and how life threatening it is.
- The people I know who don't like the idea of organ donation think it is "sick" to have their organs removed, even if they are dead. If you can get around this attitude, it will be a success.
- Perhaps testimonials from prominent recipients of organs. Or an emotional plea from someone in need - emphasize the waiting anxiety.

LOCALIZATION

- Provide useful materials to local chapters, so they can be localized. Our license and mission is to serve our local audience in terms that relate to their lives and needs.
- Localize with local phone number. I would encourage the organizations to find a local angle, make the spot hard hitting and emotional and have a media showing to local stations to debut and distribute the spot.
- Appeal to a large variety of people and localize it (tag at end). We're a small town and sometimes these services are not available locally -- an 800 number would be nice.

-Try to localize, by leaving room for a local tag or putting local phone numbers. This way the frequency of air time increases.

-A brief explanation. A toll free number to have more information sent to them. People are more likely to respond to a phone number.

-Local first! Red Cross encompasses all kinds of organ donations.
DON'T OVERLAP!!

PRODUCTION

-PSAs get the most airtime here if they are unique or inventive in some way. Produce a spot that will make me notice it -- and the audience will too.

-Maintain high production standards, i.e., proper lighting, good visual effects, correctly spelled. Also, make the spot interesting and appeal to viewer's emotions.

-Make sure the quality of the tape is superb! High broadcast quality with a message that a wide audience range can relate to.

-Contact with station; quality production; send it in the format that station prefers.

-Get best script and production values possible -- emulate successful Cleo award-winning commercials and win over PSA Directors to your cause.

-Quality of the piece -- audio-visual. Professional voice is a must. This is the first thing that either makes or breaks a PSA.

-Keep production values high and lighten the content to whatever degree possible! Give a choice of videotape format -- be very specific about kill dates.

DISTRIBUTION

-Send script and storyboard with tape -- don't ask for tape back, make it easy for us because we receive several PSAs a day.

-Send storyboards with tape.

- Don't send VHS. Keep dealings with the station short.
- Make personal contact with the P.D. and person responsible for PSAs and get to know them, find out what they want and need and work with them. Inform them about your cause and how it impacts on your area. Make them a partner, as much as they desire.
- Do something to make your PSA special -- packaging, follow-up phone calls. etc. Create an exceptional on-air product.
- Get to know the public service director and station policies on PSA placement.
- Do not rely on PSAs only -- try to tie spots locally through news/health reports.
- Send cover letter stating purpose of spot, importance, rationale and storyboard.
- Call and let us know the PSA will arrive and after we receive spot do a follow-up call.
- It really helps to send accompanying information, including what the PSA is about, how long it should air, who the target audience is, the name, phone and address of a contact person.
- Send tape to station 3 weeks prior to air date. Select a specific campaign time frame.

OTHER SUGGESTIONS

- Solicit the assistance of a local PR or media firm to develop a specific campaign: 1) awareness; 2) local examples of help; 3) future plans or developments which will provide local citizens in all demographic groups with a better life.
- I would advise you to solicit the help of an ad agency who donates their service to non-profits.
- Make sure not sponsor-ridden, i.e., "this message brought to you by...,etc."

-Plan a local campaign using all media, a local celebrity or influential person and a hospital or major medical organization sponsoring it.

-Please try to work with a local TV network affiliate to sponsor your campaign. Have your local cable (TV) company co-sponsor, if possible, so that the PSAs run on a variety of channels in addition to the Affiliate using one of their news anchors. You can often get news series out of a station's sponsored campaign and much better PSA air times and frequency.

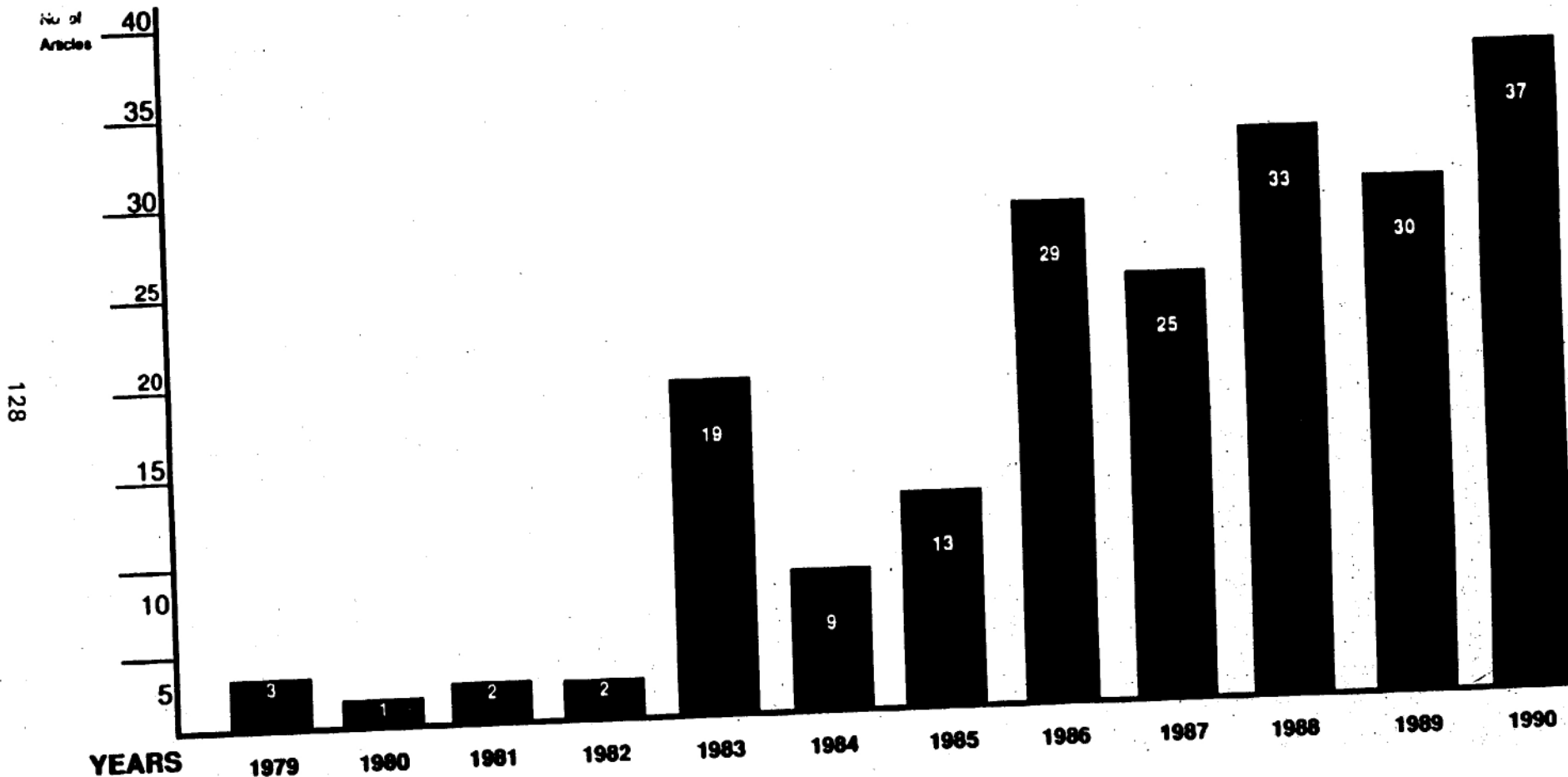
-We need more Spanish PSA (Spanish language) spots, and also involve all Radio Stations (Spanish). Seems to me that radios are the forgotten ones!

-No commercial mention of any kind in either audio or video (even if a sponsor is underwriting the production cost of the spot).

-Do not promote fund-raising efforts (We're non-profit).

Table #1 (Graphic Representation)

**NEWSPAPER ARTICLES ON
TRANSPLANTATION 1979-1990**



**Sources: New York Times, Wall Street Journal, Christian Science Monitor, Washington Post, Los Angeles
National Kidney Foundation, Inc. Survey of Newspaper Articles Relating to Transplantation 1979-1990
April 1991**

Table #2

**SUMMARY OF ONLINE SEARCH OF THE READER'S
GUIDE TO PERIODICAL LITERATURE, 1983-1990**

Topic: Transplantation

<u>YEAR</u>	<u>NUMBER OF ARTICLES*</u>
1983	59
1984	86
1985	45
1986	69
1987	72
1988	95
1989	57
1990	70

* General transplantation articles posted.

Figure #1

VISIBILITY OF ORGAN DONATION

IN 14 MARKETS
(PERCENTAGE AT EACH RATING LEVEL)

<u>SCALE</u>	<u>NKF AFFILIATES</u> N = 14	<u>ORGAN PROCUREMENT ORGANIZATIONS</u> N = 14	<u>PUBLIC SERVICE DIRECTORS</u> N = 14
*10	0%	7%	0%
9	7	0	0
8	0	29	0
7	36	43	17
6	21	14	17
5	21	0	22
4	0	7	17
3	7	0	11
2	0	0	11
1	0	0	5

* 10 = Highest rate of visibility

National Kidney Foundation, Inc. Survey on Visibility on Television Gatekeepers and NKF Affiliates and Organ Procurement Organizations Regarding Promoting Organ Donation
April 1991

Figure #2

NKF AFFILIATE & OPO ASSESSMENT

OF COMMUNITY PUBLIC EDUCATION EFFORTS

IN 14 MARKETS

	<u>AFFILIATES</u>	<u>OPO'S</u>
Make Effort for Consistency		
Yes	50%	64%
No	46%	43%
Evaluate Effectiveness		
Yes	54%	69%
No	46%	21%

National Kidney Foundation, Inc. Survey of NKF Affiliates and Organ Procurement Organizations
Regarding Promoting Organ Donation

April 1991

Figure #3

LOCAL PUBLIC SERVICE DIRECTORS

REPORTING ON PICKING UP NETWORK SPOTS

	<u>FREQUENTLY</u>	<u>SELDOM</u>	<u>NEVER</u>
MAJOR MARKETS (N=35)	3	14	18
SMALLER MARKETS (N=243)	44	140	59
TOTAL (N=278)	47	154	77
%	17%	55%	28%
		83%	

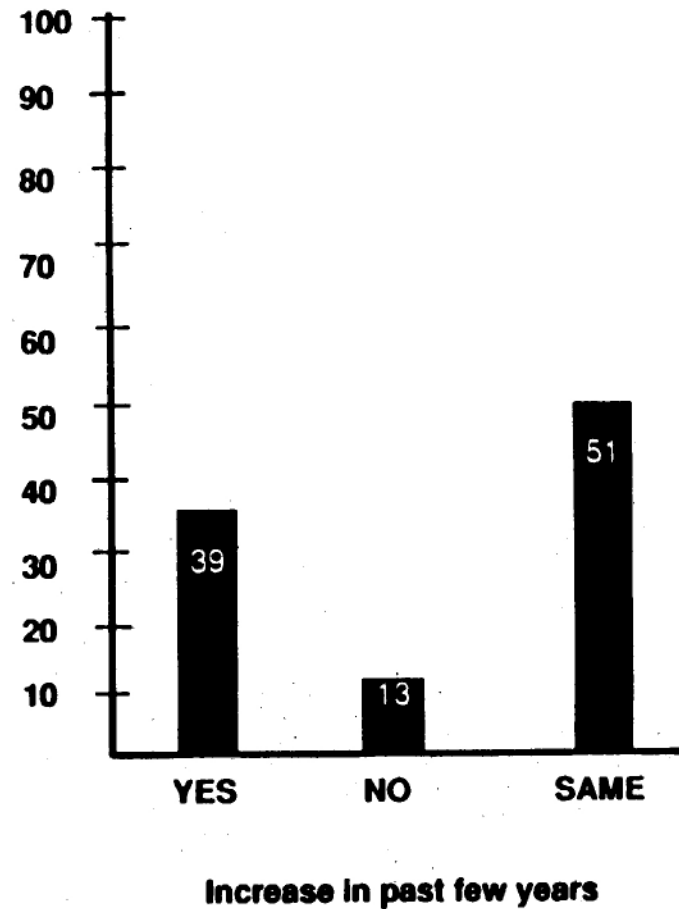
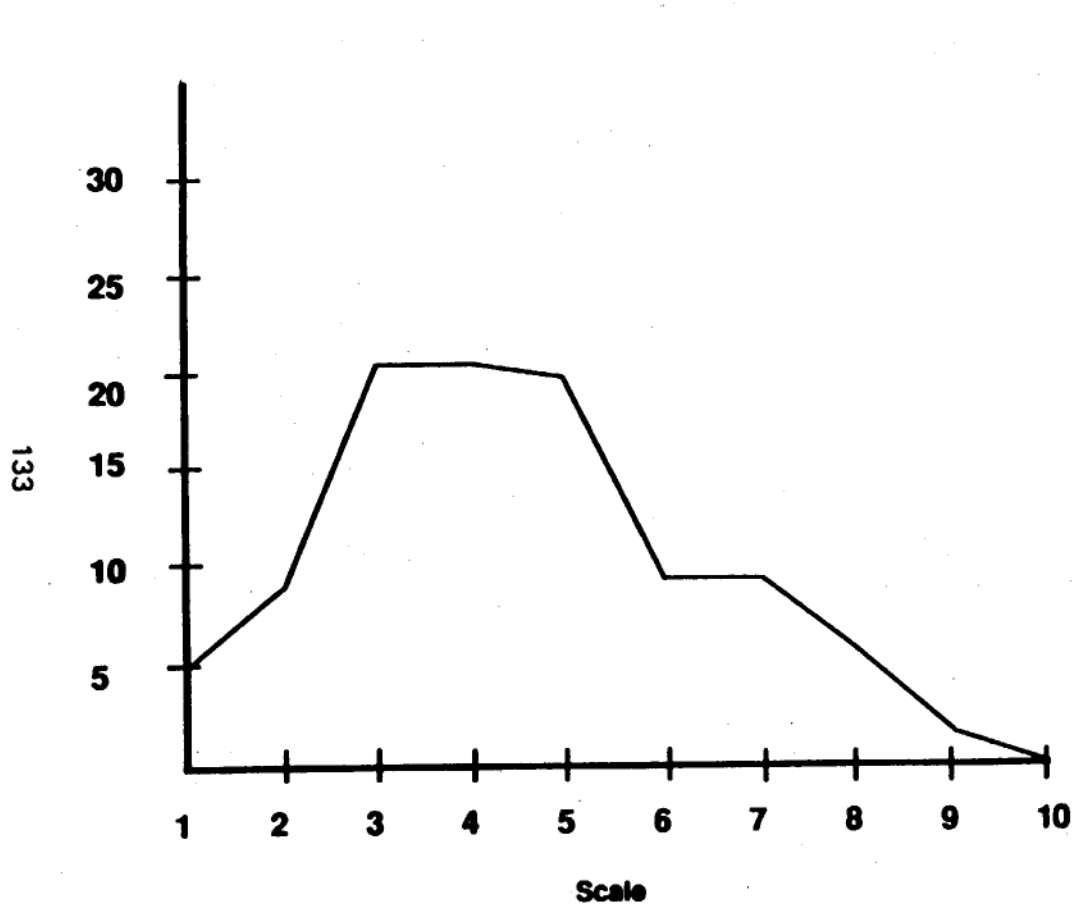
National Kidney Foundation, Inc. Survey of Television Gatekeepers Regarding Promoting Organ

Donation

April 1991

Figure #4

VISIBILITY OF ORGAN DONATION ACCORDING TO PUBLIC SERVICE DIRECTORS (N=278)

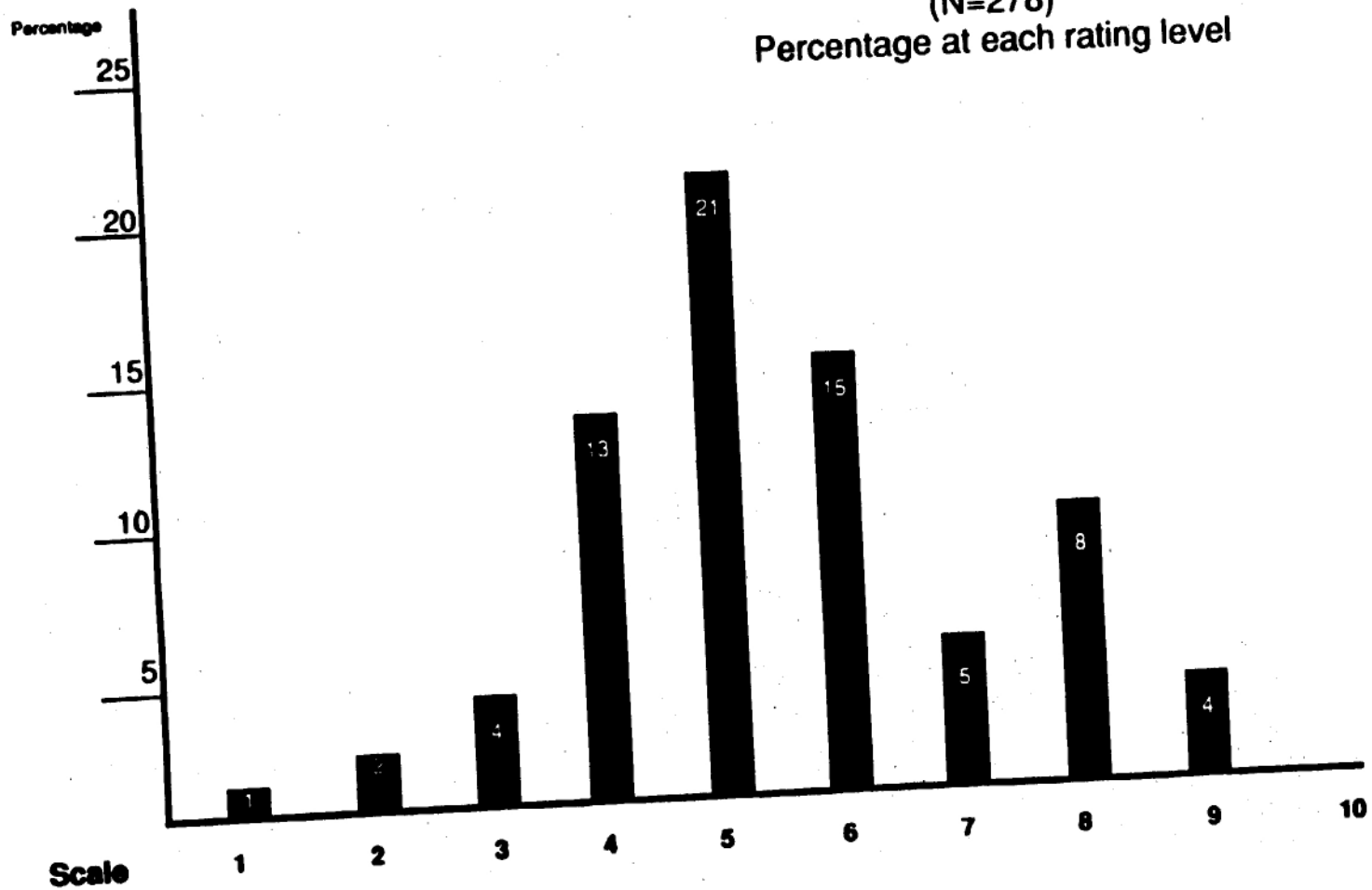


National Kidney Foundation, Inc. Survey on Television Gatekeepers Regarding Promoting Organ Donation

April 1991

Figure #5

**IMPORTANCE OF ORGAN DONATION
According To Public Service Directors
(N=278)
Percentage at each rating level**



1 = most important (AIDS RANKED #1)

National Kidney Foundation, Inc. Survey of Television Gatekeepers Regarding Promoting Organ Donation
April 1991

Figure #6

LIKELIHOOD OF PUBLIC SERVICE DIRECTORS

TO USE SPOTS

As Affected By Method of Distribution

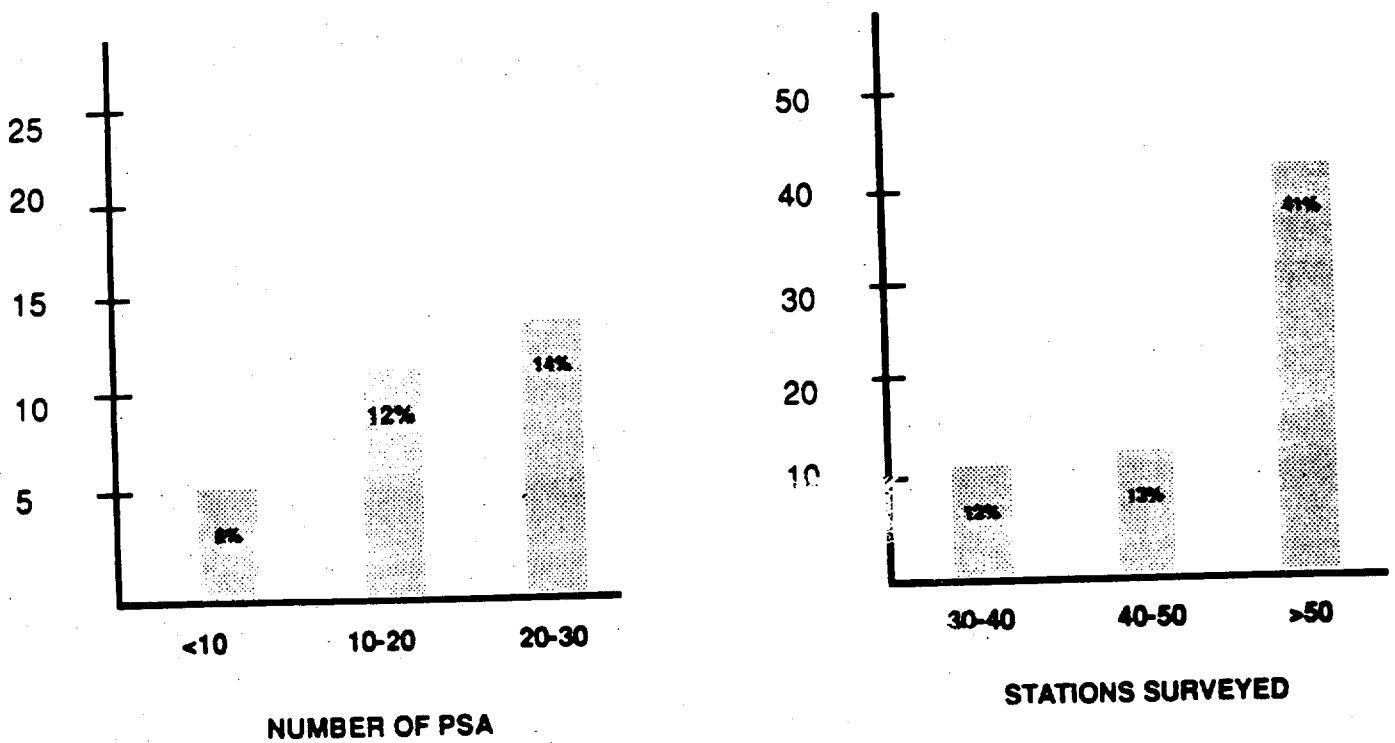
BY AN AGENCY 5%	BY HAND/ BY LOCAL REP 54%
BY MAIL 19%	ALL EQUAL 18%

Figure #7

NUMBER OF PUBLIC SERVICE ANNOUNCEMENTS AIRED PER WEEK

(N=278)

ALL SUBJECTS

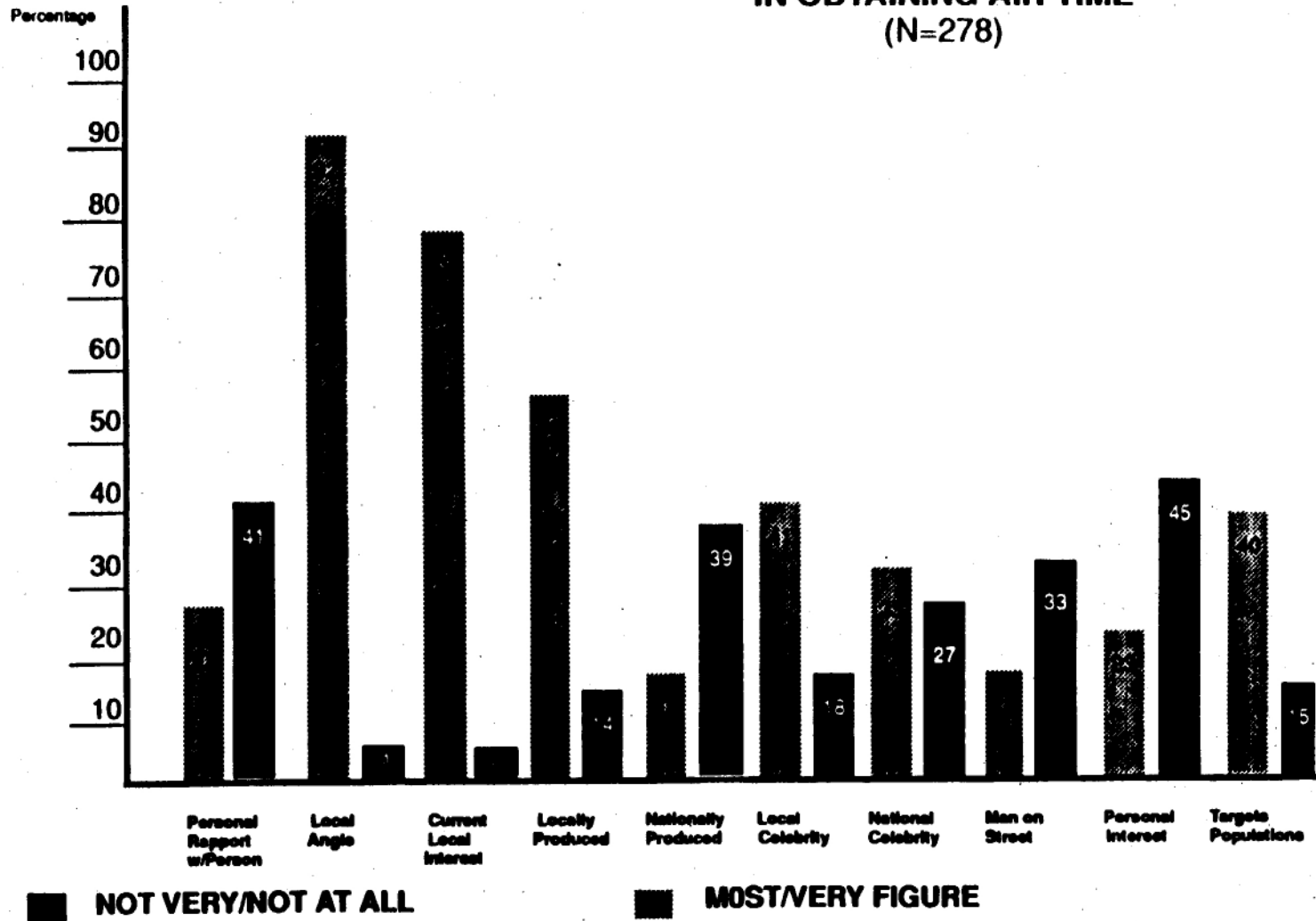


National Kidney Foundation, Inc. Survey on Television Gatekeepers Regarding Promoting Organ Donation

April 1991

Figure #8

IMPORTANCE OF VARIOUS FACTORS IN OBTAINING AIR TIME (N=278)



137

National Kidney Foundation, Inc. Survey on Television Gatekeepers Regarding Promoting Organ Donation
April 1991

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