

PLANTING THE SEED: ORGAN TRANSPLANTATION EDUCATION FOR CHILDREN, YOUTH, AND YOUNG ADULTS

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Teaching young people about organ transplantation is not notably difficult. Their lives are filled with situations ripe for discussing the topic, from school to church to community activity. The subject is intrinsically interesting, is not difficult to understand, and appeals to youthful altruism. But the organ transplant community has to offer strong inducements for teachers in various settings to take up the task.

Neither members of the organ transplant community nor teachers in schools, colleges, religious organizations, and community youth activity groups seem to want to undertake that task in any great numbers. Education efforts of the transplant community are concentrated on medical professionals and the general public. Few teachers or youth group leaders have been prompted by either their own interest or the suggestion of others to introduce the topic into appropriate situations. Strong, persistent education efforts focused specifically on young people seem comparatively rare.

Directing concerted education efforts to children and young adults would seem of clear value to the organ transplant community. Helping young people understand the facts about transplants early in life increases the chance that they will be sympathetic to the idea of organ donation should the situation arise later in their lives. They will be more willing to designate themselves as organ donors or to give permission for organ donation by next-of-kin should they be faced with such a decision. They are also likely to respond to a teacher's suggestion that they find occasion to discuss the issue with their families or with peers, thus multiplying the educational effect.

And then the possibility exists for that rare occasion when a young person who has been exposed to the subject of organ transplantation and discussed it with his or her family sadly becomes a candidate to donate organs. Exploration of the issues under circumstances free of stress makes it easier for medical professionals to gain consent for donation in the emotional upheaval attendant upon a young person's dying. A recent case in Michigan attests to the fact that such circumstances do arise.¹

This paper focuses on the opportunities available for reaching school- and college-age people with information about organ transplantation and donation and suggests strategies for gaining access to those avenues of communication. As background and point of comparison for that discussion it considers briefly the reasons why comparatively little education effort has been focused on this age group and samples the efforts that have been mounted to inform young people to see what can be learned from these programs. It concludes with some suggestions about likely educational approaches to children, youth, and young adults.

The approach to these issues is that of an educator. I have had no association with the organ transplant community prior to writing this paper and only a lay person's superficial acquaintance with the topic. But I have spent a professional lifetime in colleges and universities dealing broadly with undergraduate curriculum and instruction and 8 years as a board of education member for a large and sophisticated school system. If my comments seem technically naive to those who work daily with organ transplantation and donation and lack a feeling for the texture of their professional lives, readers will understand why. I can only hope that an "outsider's" approach may suggest some new ways of thinking about a difficult problem.

Central Problems

The old wheeze about the mule and the 2"x 4" has such staying power because there are so many situations in which "You have to get his attention first." The present topic is one of them. The problem is not that few know about successful organ and tissue transplantation or about the possibility of becoming a donor. The problem is rather that: (a) teachers do not think about the possibilities of organ transplantation as a vehicle for teaching other concepts, and (b) the topic has to compete with many similar ones for a place in the curriculum. In school and college curriculum, school-related activities, and church and community youth group programming, organ and tissue transplantation and donation just does not have the clout of the man with the 2"x 4".

Nor is the topic likely to achieve the preeminence among the concerns of this age group that would dictate its inclusion in education activities as a matter of course. The major medical/social preoccupations related to young people are sex, drugs, and alcohol. These topics are followed, at a considerable distance, by such matters as stress, nutrition, and fitness. The concerns of the transplantation community can be attached to some of these issues, but the spin that might be given organ donation in some of those contexts would not be particularly conducive to the community's message.

If organ transplantation and donation are only one among many interesting but not essential topics for curriculum planners and activity programmers, the topic has quite negative connotation for many young people, particularly late adolescents and young adults. These groups are averse to dealing with any matter that causes them to contemplate their mortality. In putting this paper together I spoke with a university health center director who works with a quite active student health advisory board. When the director asked the board chair about the possibility of the group's taking an interest in organ donation, the response clearly indicated a distaste for the whole topic. If university students most interested in health matters do not want to touch the topic, what must be the attitude of most others?

Thus, those seeking to increase awareness in the school- and college-age population should have as their first goal simply getting on the agenda. Once there, they have to be content with advancing on a broken front, trying a variety of tactics to reach audiences in several different situations, aggressively seeking out and actively creating allies where they can find them.

Given the difficulty of first getting on the agenda and then the likelihood of making only limited progress, it is no wonder that organizations trying to increase the number of organ and tissue donations have concentrated their public information and education efforts on other audiences. Organ Procurement Organizations (OPOs) focus most of their efforts on medical professionals, particularly those in hospitals. Hospital staff members are at the point of contact when the question of organ donation arises in earnest. They are at the most proximate source of potential donations and are legally obliged to ask the appropriate person about willingness to have the dying person's organs or tissues donated. It only makes sense to concentrate education efforts there.

It makes even more sense considering the pressures OPOs are under from Federal regulators. The pressure now is on the bottom line: increasing the number of organ donations immediately. Broader public education, particularly focused on young people, takes time to produce results. The logical conclusion: given limited personnel and funds for education activities, redouble efforts at reaching the proximate source and making efforts more effective.

Education programs for hospital personnel, however, seem for the moment to have achieved as much as they are going to. Indeed, that is why the Surgeon General's Workshop is being held. Organ donations seem to have peaked and the transplant community is looking for ways to increase them. It may be that a substantially different approach with hospital personnel will achieve improved results. It may be that better public education will result in more receptivity to organ donation. But it is quite clear that the present effort to arm hospital personnel with the applicable facts, laws, strategies, and attitudes is not producing the number of organ donations needed and the nets have to be cast more widely.

Associations focused on health issues related to a single organ or type of tissue (e.g., the National Kidney Foundation, the American Heart Association) also conduct extensive public education campaigns. Their efforts, however, focus on a wide variety of issues of which organ donation is only one. (When they do talk about organ donation, however, they tend to talk about donation of all organs and tissues, not just those that are the focus of their association.²) The greatest amount of money and effort goes into media campaigns and other activity directed to the general public. The Source Book of the American Council on Transplantation, a compendium of programs for public awareness about organ and tissue transplantation and donation published in 1988, lists fewer programs directed at young people than can be counted on the fingers of one hand.

So just as one wonders about the potential for improved results from the OPOs' educational focus on health care professionals, one has similar doubts about the ability of these associations' public campaigns to increase organ donations. More specifically targeted education programs, among which are activities for children, youth, and young adults, are at least worth considering.

Efforts to Reach Children, Youth, and Young Adults

Contacts with key members of the organ transplant community nationally and in major population centers have turned up only scattered examples of education materials and programs specifically directed at young people. By far the most prevalent such efforts are presentations for school classrooms and assembly programs.

Typically, the offer to conduct such a program comes from the education section of an OPO or association, although some organizations outside the transplant community, such as the Junior League, have taken a specific interest in organ donation education. The group wishing to present the program sends a request to a school official: superintendent, curriculum supervisor, or principal. Sometimes the request is routed to a teacher who might wish to schedule such a presentation, sometimes it goes in the wastebasket or languishes on the principal's desk. Occasionally a teacher responds and the session is scheduled. Thus, of many seeds sown, only a few germinate.

The more successful programs target teachers, who have the most direct control over the day-to-day content of classroom instruction. The problem is getting names for an accurate mailing list and following up with personal contacts. OPOs and association regional offices cover large areas with many schools and school systems. They have limited staff to devote to identifying the likely targets by name and contacting them in such a way as to maximize the possibility of gaining

entry to the classroom. The best solution has been finding a receptive school system and concentrating efforts there before moving on to another interested system.

Once having achieved a strong position in a school community, the problem is to continue arranging presentations in those schools year after year while expanding the program of classroom presentations to other systems. No organization I located had been carrying out a focused program long enough to have faced that problem.

Prior to initiating contacts with schools and school systems, organ donation educators must decide what part of the school curriculum they wish to target. Would they most wish to present an assembly program or speak to students in a particular course such as health education, driver education, biology, or general science? Do they wish to reach elementary school students or concentrate on the secondary schools? Clearly, different programs are required for different situations: one size does not fit all.

Tailoring the presentation involves knowing how to relate the material to the general purposes of the course and the content of classes immediately preceding and following it. A talk in a driver education class, in which the context is agreeing to sign the organ donor form, should be differently designed than a presentation in a health education course which is part of a unit on organ systems.

These distinctions do not appear to be clearly made. The presenting agencies most frequently have an all-purpose videotape that is the focal point for the presentation. The agency representative introduces and bases comments on the tape. Most such presentations incorporate, if at all possible, an organ recipient or the relative of a recipient, most desirably a person close in age to the audience. Frequently the main presenter is such a person. Sometimes a physician is included in the presentation.

This general format is designed for a one-time, stand alone presentation. It is quite effective in increasing awareness and knowledge about organ transplantation and donation and beginning to dispel myths. The comments of recipients and their families, either on tape or in person, leave a strong impression, but one does not know how long the impression lasts or what specific results it produces. We have only anecdotal information.

Some teachers are perfectly satisfied to have a presentation unattached to the general design of their courses. If some more organic connection needs to be made, they will make it. Conversely, I suspect that at least some of the resistance to presentations on organ donation in health and science classes is due to the perception that it will not work into the flow of the course, that it will be an

interesting but not notably relevant side trip. Teachers need to see how the subject of organ transplantation can be used in connection with a particular topic to illustrate a general point. Understood this way, organ and tissue transplantation could be dealt with in studying the immune system, organ systems, science and public policy, medical ethics, or social psychology.

This same tendency to treat organ transplantation and donation as an unrelated topic is manifested in the curriculum materials that various groups have produced and distributed. Even when the materials have been designed for use in a particular course, the assumption seems to be that the teacher is to treat the subject on its own terms rather than as a specific case of a more general issue. For example, a unit on "Donating and Transplanting Organs and Tissues" designed for eighth grade health education classes lists these objectives:

- Students will develop an understanding of issues concerning the donation and transplantation of human organs and tissues.
- Students will identify which parts of the human body may be donated to promote the improving and/or saving of another individual's life.
- Students will identify at least three common misconceptions surrounding the issue of donating human body parts.

These objectives, or for that matter any other part of the unit, give no clue as to why the student ought to be learning this material, or to what other aspects of the students' personal or educational experience this knowledge might attach.

The few curriculum guides I have been able to locate and classroom materials, such as coloring books, I have seen are not a reasonable basis on which to generalize about other instructional supports that may be available, if indeed any exist. Two guides are clearly expected to be used in specific situations, one for driver education classes, one in a religious education context. The driver education guide, except for its emphasis on the Uniform Anatomical Gift Act and the Uniform Donor Card, could be used in any situation. So could the materials designed for a religious setting. They are not sectarian and differ from the public school materials only in their greater emphasis on altruistic motives and empathic responses.

All the curriculum guides focus on mastering the vocabulary of anatomy and organ transplantation at a level appropriate to students' ages and to provide some exemplary cases through which to understand processes and issues. Sample word games and coloring books are provided for younger children, model tests and discussion topics for older ones. All seem designed to persuade students to adopt certain attitudes or, in the case of older students, sign a donor card. All could be strengthened to some degree by less tendentiousness and, in the case of older students, more emphasis on ideas to discuss and less on producing right answers. When a teacher's guide is provided, it offers far less information than instructors

are likely to need and employs some technical vocabulary which teachers should not be expected to know. In short, these curriculum guides offer some useful ideas and materials, but as the controlling documents for a unit are rather a mixed bag.

Apart from the standard approaches to curriculum and instruction offered by these guides, some unusual programs and resources are worth attention:

"Debbie Donor Doll" is produced by Soft Sculptured Dolls of Dallas, Texas. "She" is a child-sized soft doll who can be zipped open to reveal removable cloth organs and tissues attached by Velcro tabs. Children can see where the organs are located and can "transplant" healthy organs and tissues.

"The Kids on the Block" is a program designed originally to help young children understand the problems of their differently-abled peers. The "Kids" are large puppets worked by trained performers. Ideas are communicated by and through the puppets. The program has been extended to deal with such problems as sexual abuse and substance abuse. Recently, Tennessee Donor Services contracted with The Kids on the Block, Inc. to develop an organ donation and transplantation program which is now available to any OPO.

"Teens for Transplants" is a program of the American Organ Transplant Association (AOTA) working with the High School for Health Professions in Houston, Texas, LifeGift Organ Donation Center, and the Texas Medical Center. The 40 students involved are all considering careers in the health professions. Through the program they get a sense of the possibilities their future work might offer by providing one-on-one peer support for young transplant patients at the Medical Center, engaging in donor awareness programs focused on minority communities, and learning what it is like to do organ transplant work as a health professional. AOTA has formed a new division to propagate the program.

Use of **The Kids on the Block** represents a good example of getting organ and tissue donation into the curriculum by using the topic to serve a larger purpose. The puppets teach responsible social behavior by providing young children with an avenue for discussing their social attitudes. The strategy encourages honest expression of feelings and reduces the risk of such expression. The general goal of encouraging empathic response, surely an important purpose of early elementary schooling, can be approached through a variety of subjects, of which organ and tissue donation is one. Thus the topic gets attention in a way integral to the curriculum.

Teens for Transplants is a fine example of using extracurricular activities as a way to reach young people. To be sure, siting the activity at a high school whose program is designed for future health professionals gives it a chance for success rarely duplicated, but such an activity does not require such a setting. All sorts of service-oriented clubs and activities find fertile soil in high schools, appealing to many teenagers' altruistic instincts. Indeed, organ and tissue donation organizations may find their time better spent in approaching students through the extracurriculum than through the curriculum. At both high schools and colleges, service clubs and student government groups are looking for suitable projects. Donor awareness activities within the school or the community meet their needs well and give the organ transplant community an opportunity to educate a group of students in a setting providing more receptivity than the classroom.

Transplant education agencies should be aware, however, that sustaining such activities over a number of years requires a lot of effort. Teens for Transplants chapters have a good chance of lasting because they are focused on a single concern in much the same way as Students Against Drunk Driving.

If, however, the leadership of a student government association or service club gets excited about organ donation and mounts an excellent effort in that area, there is no guarantee that the effort will ever be repeated. Student organization leadership changes every year and the next year's leaders may have other enthusiasms or less ability. The University of Pittsburgh chapter of Mortar Board, a national undergraduate service honorary, involved four Pittsburgh area colleges in a highly successful organ and tissue donor awareness program in 1985. Different leaders the next year had other interests or less energy and the effort has never been repeated despite the excellent project documentation the graduated leaders left behind.

The only college and university program at the national level is an activity program for National Organ and Tissue Donor Awareness Week put together by the American College Health Association, a group comprised principally of health center directors. The Association put together a packet of educational materials, suggestions for publicizing the Donor Awareness Week, and ideas for activities. These materials were made available at no cost to campus groups interested in using the occasion to increase public awareness.

Apart from this program, any attention paid on college campuses to organ and tissue transplantation and donation appears to be a matter of the interest of individual faculty members. A number of social scientists have research interests in this area. The research subjects are frequently college and university students. In their involvement in these experiments, which deal with attitudes toward transplantation, students may end up learning a good deal about the issue.³

Information about the efforts of student organizations on college and university campuses is likely to be fugitive. No information exists about OPOs or associations directing their efforts toward postsecondary education and individual campus efforts are probably scattered and short-lived. There may be a fertile field there, but no one seems to have plowed it.

Conclusions

Efforts specifically directed at informing children, youth, and young adults about tissue and organ transplantation are scattered and of variable sophistication. In few cases are they the principal focus of someone's job. The programs brought into schools and the materials made available to teachers, approach transplantation and donation from the point of view of the transplant community rather than that of the curriculum. The most imaginative and successful programs reflect an understanding that transplantation stands a better chance of becoming a subject of instruction as an illustrative example of a more general topic than as a topic in and of itself.

The possibility of reaching young people through extracurricular and community activities remains largely unexplored. Despite the difficulty of sustaining programs once they are successfully begun, the possibility of payoffs from young people's altruistically motivated volunteerism would appear to make the effort worthwhile.

Reasons for transplant educators' marginal efforts to mount programs specifically directed at the school- and college-age population are quite understandable. Education activities are the concomitant rather than the focus of OPOs' activities. They have comparatively little funding and staff for education and must devote most of their attention to hospital personnel. General public education comes second, with programs targeted at specific populations third. Only now is the realization growing that targeted campaigns may produce better results than broader efforts. But they are also more expensive of staff time.

OPOs now find themselves in a particular squeeze. Newly proposed Medicare regulations make immediate increases in organ procurement a necessity for survival. Education programs aimed at young people produce most of their results over the long run. OPOs feel the need to focus their efforts in areas that will produce the most immediate results.

As the number of OPOs decreases, the geographic area assigned to any one OPO increases. That enlargement of the service area makes it all the harder to maintain the personal contact with individuals in schools and colleges whose interest and cooperation is essential to a successful program for students.

The associations, on the other hand, are in the business of education, but transplantation is only part of that business. They are concerned about health maintenance, support for research, and treatments short of transplantation before they get to the transplantation issue itself. The associations, too, are beginning to think more about education programs for particular groups, but they still rely mostly on public service announcements, posters, bookmarks and national awareness days and weeks.

Even with time and determination, schools and colleges are difficult to penetrate. No curricular priority creates a reason for classroom discussion of organ transplantation and donation any more than dozens of other scientific, medical, or public policy matters. Requests for the schools' curricular attention are overwhelming. One health education curriculum coordinator reports 400 solicitations a year for adoption of particular texts, inclusion of units of study, and purchase of teaching materials. Only occasionally does an item that comes in over the transom get adopted.

The main focus of programs in schools is one-time presentations in assembly programs and health and driver education classes. All-school assemblies are the best setting for the kind of presentation transplant organizations are prepared to make, but fewer and fewer schools even have such events.

Driver education classes, too, are a fading feature of school life, but talk about organ donation has a clearly identifiable place in such courses. Even though curriculum materials for the most part conveniently neglect the fact that a signed organ donor card is for practical purposes meaningless as a form of consent to donating one's organs, discussion of donation and the signing of the Uniform Donor Card is valuable. The discussion itself raises awareness. If students then introduce the discussion at home, the matter comes to the attention of their parents, most of whom are in the age range that produces the most donors. Most important of all, signing the donor card is for many students one of the first acts of assuming adult responsibility for the general welfare.

Health education and biology classes in the secondary school and the science curriculum in the elementary school would seem the most logical place for discussion of transplantation. However, the approach to the inclusion of units on transplantation here is far too limited and educators have shown very little imagination about exploring other curricular areas in which to embed their message.

Penetrating the college curriculum requires more effort than the result would justify. Decisions about course content at the level at which transplantation discussions might occur is entirely in the hands of individual faculty members. Trying to identify the few who might find that organ transplantation or donation

provides a good vehicle for illustrating a point they would like to make is not a good investment of time.

The best entry to post-secondary institutions is through student groups: fraternities and sororities, service organizations, honorary societies in various disciplines. This approach through the extracurriculum holds promise for high schools as well. Organ donor education groups must, however, be prepared to deal with the problem of sustaining effort. Either they must accept the fact that a program successful one year may die the next or be willing to provide the kind of organizational support that will keep the program intact through periods of weak or uninterested student leadership.

While the lives of most young people center on their schools and, for half the 18-21-year-olds, on colleges, people in this age group are also involved in community activities: church groups, boys' and girls' clubs, scouting, 4H Clubs, Little League baseball and its equivalent in other sports, youth auxiliaries of adult organizations, and so on. Focused efforts to reach the African American community have used churches as a vehicle. In recent years the Boy Scouts offered an opportunity, now discontinued, to earn a merit badge in organ and tissue donation awareness. Otherwise the transplant community seems to have ignored the possibility of reaching young people through their community activities and concentrated instead on the schools.

Despite the major pitfalls and the investment of staff time necessary to mounting a successful education program aimed at young people, the potential payoff is worth the effort. Current strategies have brought organ and tissue donation to a steady state. Moving to the next quantum level requires new strategies. Young people are a large group whose characteristically sympathetic response to others' needs makes them a receptive audience for the transplant community's message. In the classroom setting they are also, to put it bluntly, a captive audience. But if the message can be carried by an appropriately designed vehicle, the topic of organ transplantation is of sufficient inherent interest to engage their attention. They then become a conduit for discussion of organ donation at home, producing, ideally, a multiplier effect. And as they mature and are perhaps called upon to make decisions about the donation of others' organs, they stand a good chance of being more receptive to the notion, having better factual knowledge.

Those young people who find the matter of organ donation particularly compelling are a prime source of volunteers. They have time, energy, and commitment which can easily be put to use by regional associations, OPOs, and the like. If only as a means of recruiting volunteers, the efforts to reach children, youth, and young adults may be worth the time.

To succeed in these efforts, educators in the transplant community need to mount persistent and coordinated efforts. Such efforts may not be possible for regional organizations whose attention is pulled in many different directions and whose funding is unstable. Coordinated efforts beyond the regional level and funding targeted for specific education efforts would be helpful. It is clear that the current level of effort which with rare exception is occasional, casual, and unsystematic will not begin to tap the enormous potential that young people hold for increasing the level of organ donation.

Recommendations

In making recommendations, I am tempted to suggest that the organ transplant community try all the avenues that seem plausible to reach young people. Since so little has been tried and the efficacy of so much of that has yet to be demonstrated, it is hard to know what will work.

Many of the following recommendations are suggestions about practical matters of procedure on the local scene rather than matters of policy or practice on a larger scale. The focus on particular practices grows from a perception that, at least for the time being, education programs will be carried out by regional groups and by people largely unfamiliar with the way schools and colleges work. Thus my first desire is to help avoid wheel spinning.

A. Curriculum

(1) Design curriculum guides and classroom presentations as an integral part of the course of study rather than as stand alone segments. Organ transplantation and donation as a topic in and of itself really has no natural place in the curriculum except perhaps in driver education. As a specific case of a general principle, however, it fits in countless places. For example, the topic can be introduced in studying the immune system in biology, anatomy, and physiology courses; in studying human anatomy in a health course; as a public policy issue in a political science or current events course; or as a science and ethics issue in a general science or philosophy course. Any good teacher, unless he or she has a personal interest in the topic, will want the curricular materials or presentation tailored to the purposes of the course.

(2) Curricula and presentations should acknowledge some of the complexities surrounding organ transplantation and donation, as is appropriate to the understanding of students of the age for which the materials are designed. Too much of the material suggests that if all the myths were dispelled, organ transplantation as it is currently practiced would be seen as an unmixed blessing. Questions about such matters as organ sharing among OPOs, who gets organs,

and cost-benefit issues should be introduced and discussed. While one does not expect elementary school students to raise such questions, older students are not so naive and need to have these issues dealt with honestly.

If a major purpose of donation and transplant awareness activities in schools and colleges is to get the issue discussed around the dinner table, then **(3) all programs and curricula should include strategies students can use in introducing the topic at home.** Even in the most structured situations students cannot absolutely be required to raise the issue, but they can be strongly urged and helped to do so.

B. Dealing with schools

(4) Focus efforts on people who are the real decision makers about curriculum. Superintendents and principals almost never make decisions about particular items of curriculum. Those decisions are, to all intents and purposes, made by curriculum coordinators at the system level and individual teachers at the school level. Except in rare instances when the superintendent has a strong personal interest in seeing that organ and tissue transplantation gets some curricular attention and wants to do something throughout the school system, he or she will not want to get into the matter at all. Even working through the curriculum coordinator, the best likely result at the system level is introduction of an optional unit for teacher consideration. The best way to get on the agenda is to work with individual teachers.

Given these facts of curricular politics, writing letters about available programs or curriculum materials to superintendents and principals is not cost effective. Even writing to individual teachers will yield no better results than one might expect from a direct mail campaign. **(5) Contact the relevant decision makers personally,** presenting to them options for materials and presentations that are specifically geared to topics with which the curriculum for that course deals. That strategy requires a lot more preparation than offering a canned program and probably requires a representative of the organ donation agency who knows something about curriculum. **(6) Where possible, agencies should employ a staff person with a good knowledge of school curriculum.** As I have frequently suggested, the transplant community may more effectively get its message into schools through student clubs and organizations than through the classroom. **(7) Organ transplant educators should try enlisting student organizations such as service clubs, student government associations, Students Against Drunk Driving, or peer counseling groups in their efforts.** An active, carefully guided donor awareness effort by a student government can educate a whole generation of students and perhaps produce some volunteers for the OPO or organ association in the process. Even if the program is not picked up by the organization in the following year an advantage has been gained.

More likely to have staying power are organizations like Teens for Transplants. Such an organization has donor awareness and volunteer work with patients as its purpose for existence. A charismatic advisor can get such a program well established and give it a strong basis for longevity. **(8) The organ transplant community should support the efforts of the American Organ Transplant Association to establish Teens for Transplants organizations in high schools.** Student organizations do not generally exist on the elementary school level. Other than the classroom, the best point of entry for elementary schools is the PTA. **(9) OPOs and association chapters should work with PTAs to design programs suitable for their meetings.** PTAs are always looking for topics for programs. Organ transplantation and donation is an interesting topic with some personal relevance to individuals in almost any community. If a central purpose of getting organ and tissue transplantation into the school curriculum is to get the topic discussed in the family, PTA programs would seem a more direct way to achieve that result.

All of these strategies are easier to implement if one is dealing with school people who have a prior interest in organ and tissue donation. People who have themselves been organ or tissue recipients or close relatives of recipients are natural allies. But one may also create allies by enlisting them in the cause.

(10) Agencies should establish education advisory committees composed of people influential in the local education community. A curriculum coordinator, a PTA president, a science department head at the local university, an influential teacher can provide useful advice on designing programs directed at young people and can become active players in facilitating their adoption. Although the care and feeding of such a committee takes some time and thought, members' support for the agency's education activities can be well worth the effort.

C. Postsecondary Institutions

In postsecondary institutions, the best approach is through student organizations. Fraternities and sororities are always looking for public interest projects. While some efforts are short-lived, others may go on for years and become part of the life and character of the organization. Service honoraries are often similarly at a loss for services to provide. Since they turn over their membership completely every year, getting an activity rooted is more difficult, but encouraging a one-time effort, if it is substantial, may be worthwhile. **(11) Donor awareness groups should work with undergraduate organizations to mount donor awareness projects.** Opportunity may even exist to create an analog of the Teens for Transplants program on college campuses, using pre-medical or health education students as its basis.

D. In the Community

Many untested opportunities exist for reaching young people through the community. The only particular model that has been used often enough to suggest some promise is using religious schools and youth groups as an avenue for education. **(12) Donor awareness groups should work with churches and synagogues to identify opportunities for youth education and service activities.** Beyond the religious groups, a variety of youth organizations offer possibilities. **(13) Donor awareness groups should make an informal inventory of youth groups in their service areas to determine which offer structures conducive to awareness activities and have supportive adult sponsors.**

E. Research and Funding

Of 29 awards made in 1988 and 1989 under the Division of Organ Transplantation's grant program for OPOs, only two were for education activities directed at children and youth. Given the disincentives for addressing this population, substantial activity will require far more support and specifically targeted funds. **(14) The Division of Organ Transplantation (DOT) should seek funds to establish a grant program to encourage donor awareness programs designed for children, youth, and young adults.**

Such a grant program could be included in the activities of a Donor Education Network with the responsibilities recommended by the American Council on Transplantation (ACT).⁴ This Network's purpose would be "to coordinate the many separate public education initiatives conducted by transplant-specific, transplant-related organizations, and organizations that are interested in the cause of organ and tissue donation and transplantation on a project-oriented basis." Developing materials for education programs of many different kinds and to address many different audiences is clearly much more than any single organization can take on. There is not even a good mechanism for sharing ideas or collaborating on program and materials development. A coordinating body could facilitate development of more sophisticated materials and strategies geared to a variety of audiences. **(15) The DOT and the organ and tissue transplantation community should take steps to create a Donor Education Network.**

The Network, among other tasks, could foster research on the effectiveness of education activities. The ACT found that nearly half of public education programs incorporate no evaluation.⁵ The summaries of the DOT grants indicated no provision for evaluation. Clearly research on the effectiveness of these programs is necessary. **(16) The DOT should use part of its 1 percent evaluation funds to assist grantees in evaluating their programs.**

In Conclusion

Organ and tissue transplantation and donation education programs for children, youth, and young adults are in an early stage of development. Substantial efforts are few and time and money for them are limited. Most are not very sophisticated in the way they approach schools and school curriculum. The range of types of programs is narrow and the avenues of approach to young people have not been widely explored.

Scattered examples of reasonably successful programs exist, though some of them have been short lived. These programs can form a basis for expanding activity if funding and the regulatory climate will allow. But the effort needs a boost of both national attention and funding if it is to get off the ground.

1. Letter from Eleanor Forlenza, Administrator, Transplant and Health Policy Center, Ann Arbor, MI, to Judith B. Braslow, Director, Division of Organ Transplantation, March 13, 1991.

2. American Council on Transplantation, "Executive Summary" of "An Assessment of Public Awareness Initiatives Promoting Organ/Tissue Donation and Transplantation: Findings and Recommendations," 1990, p. vi.

3. Several reports of behavioral science research on attitudes and behaviors with regard to transplantation, using college students as subjects, are reported in Organ Donation and Transplantation: Psychological and Behavioral Factors, ed. James Shanteau and Richard Jackson Harris (Washington, DC: American Psychological Association), 1990.

4. Executive Summary, p. iii.

5. ibid., p. vi.

SOURCES

This topic calls for a listing of the sources of helpful, practical information. The listings that follow are partial, reflecting only what the author was able to discover in the course of writing this paper.

Books

American Council on Transplantation, The Source Book 1988: A Master Reference to Increasing Public Awareness About Organ and Tissue Donation and Transplantation (1988).

Organ Donation and Transplantation: Psychological and Behavioral Factors, ed. James Shanteau and Richard Jackson Harris (1990), American Psychological Association.

Reports

American Council on Transplantation, "An Assessment of Public Awareness Initiatives Promoting Organ/Tissue Donation and Transplantation: Findings and Recommendations" (1989).

Task Force on Organ Transplantation, Organ Transplantation: Issues and Recommendations (1986), U. S. Department of Health and Human Services, Health Resources and Services Administration.

Curricula and Teaching Materials

National Kidney Foundation of Eastern Missouri & Metro East, St. Louis, MO, "Giving and Receiving the Gift of Life." (Materials designed for use in a religious education environment. Separate curricula and materials for K-3, 4-6, Junior High School and High School).

Transplant and Health Policy Center, Ann Arbor, MI, "Donating and Transplanting Organs and Tissues: An Eighth Grade Module."

Transplant Recipients International Organization (TRIO). Various classroom handouts and instructional activities.

The Virginia Transplant Council, Richmond, VA, "Organ and Tissue Donation Curriculum Guide." Both a general purpose guide and one designed specifically for driver education classes.

Programs of Interest

American College Health Association, Organ Donor Awareness Week materials for use on college campuses. Contact: Richard Fasano, Southern Illinois University, Carbondale, IL.

American Organ Transplant Association, Missouri City, TX, "Teens for Transplants."

Junior League of Baltimore, "Second Chance."

Junior League of Pittsburgh, "Organ Transplant Outreach Project."

Mid-America Transplant Association, St. Louis, MO. Schools outreach project. Contact: Theresa Parks-Thomas.

Tennessee Donor Services, Nashville, TN, "The Kids on the Block, Inc." Contact: Elizabeth S. Nuckolls, BSN.

Teaching Aid

"Debbie Donor Doll," available from Soft Sculptured Dolls, Dallas, TX.