



Center for New Democratic Processes

Project Director: Paul Schaefer, Ph.D.

1116 Plymouth Building

Minneapolis, MN 55402

(612) 333-5300

Citizen's Panel on Transplant Policy
Advisory Committee

Mila Ann Aroskar, Ph.D.

Nancy Ascher, M.D., Ph.D.

Andrew P. Czajkowski

Frazier Eales, M.D.

Bernard Gersh, M.D., Ph.D.

David Graven

Ronald Hamel, Ph.D.

Thomas Jolicoeur

Daniel J. McInerney

Laird Miller

Evelyn Van Allen, M.P.H.

Neal A. Vanselow, M.D.

PRELIMINARY REPORT

CITIZENS PANEL ON TRANSPLANTS AND PUBLIC POLICY

November 22, 1986

This Preliminary Report of the Citizens Panel on Transplants and Public Policy was issued on November 22, 1986 at 2:30 P.M. As such, it represents the views of the panelists as they completed their work on that day. The language of the findings and recommendations has been reviewed by the Panel and they affirm that it represents their views. There has not yet been a chance to present Appendix B to the witnesses to see if they concur that it is a fair summary. The panelists, however, did get a chance to review it and they believe that it is a fair summary of the testimony presented.

A Final Report will be issued by the Center for New Democratic Processes in January of 1987. This will not contain any changes in the findings and recommendations, but it will contain a fuller analysis of the project and may contain additions and/or corrections to other sections of the report.

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SECTION 1

EXECUTIVE SUMMARY

The Issue

There is wide agreement that in Minnesota there is a shortage of donor organs for transplant purposes. One way to deal with this would be to pass a law requiring hospitals to ask families of potential donors to consider organ donation. Should Minnesota adopt such a "required request" law? If this is done, then this implicitly supports the idea that society should be investing more health care resources in individual-oriented programs such as heart transplants. Might it be wiser to invest equal or larger amounts in population-oriented programs such as public education about the health risks of tobacco use?

The Process

Citizens Panels are a process created by the Center for New Democratic Processes to involve citizens in public policy decision-making processes. In this project, 24 randomly selected people heard testimony from nine expert witnesses and reviewed other materials relevant to the above issues. Like a jury, the panelists were paid for their participation. Considerable attention was given to making the process fair and ensuring that the influences of staff bias were kept at a minimum. The panelists engaged in numerous small and large group discussions, leading to a set of recommendations. These will be reviewed by the Advisory Committee, who will then recommend how a full project should be conducted in 1987 on one of the above (or some related) health care issues.

The Recommendations

By a margin of 16 to 8 the panelists voted that they would like to have Minnesota implement required request. What they liked best about it is that it would increase both the number of donors and the number of organs available for transplants.

By a majority of 23 to 1, the panelists approved of more funds being spent on individual-oriented programs, such as heart transplants. Half the panelists approved of more funds being spent on population-oriented programs, such as public education about the health risks of tobacco use, while the rest were neutral or disapproved.

By a 23 to 1 majority, the panelists voted that Citizens Panels are a good method for studying health care issues in Minnesota. The issues which could be studied in addition to organ transplantation include AIDS treatment and prevention, health care for the elderly, education about family and societal responsibilities for preventive health care practices, cost of health care, health care for the homeless, environmental policies which would promote better health care, and teenage pregnancy.

SECTION 2

WHO WAS BEHIND THIS PROJECT?

PANELISTS

| | | |
|----------------------------------|-----------------------------------|---------------------------------|
| Roxanne Bakke Shoreview | Shirley Gould Mound | Terry Melton Fridley |
| Michael Beaudry Minneapolis | Betsy Haack St. Louis Park | Micki Mordh Golden Valley |
| Mary Blair Burnsville | Norman Hagen Champlin | Robert Press Minneapolis |
| Charles Blanchard Minneapolis | Robert Dale Hanson Minneapolis | Connie Quinn Burnsville |
| Marie Bonasera Minneapolis | Greg Hennek Champlin | Karl Rosengren Minneapolis |
| Renee Brinkman Apple Valley | John Hoenigschmidt Robbinsdale | Sharon Slye Minneapolis |
| William Buckley Lakeville | Mark Johnson Minnetonka | Donald Snyder Savage |
| Dione Eacock Bloomington | Pam Laughlin Edina | Shannon Terry St. Louis Park |

STAFF

| | |
|----------------------|----------------------|
| Project Director: | Paul Schaefer, Ph.D. |
| Administrator: | Judy Carpenter |
| Community Relations: | Bruce Miller |
| Moderator: | Ned Crosby, Ph.D. |
| Support Staff: | Karen Coombs |
| | Doug Nethercut |
| | Dianna DuBois |
| | Martha Ward |
| Actors: | Barbara Barker |
| | Barbara Brooks |
| | Marti Grant |
| | Steve Hollenhorst |

WITNESSES

Robert C. Anderson, M.D.
Chief, Kidney Transplant Program
Department of Surgery
Hennepin County Medical Center

Craig Ayers, J.D.
Assistant State Negotiator
Department of Employee Relations

Kathleen Daly, M.P.H.
Minn. Cntr. for Nonsmkg. & Health
Minnesota Department of Health

Sandra Griffin, R.N.
Staff Nurse, Transplant Section,
University of Minnesota Hospitals

Thomas Kottke, M.D.
Ass't Prof. of Med. and Pub. Health
Univ. of Minn. Hospital and Clinic

W. Steves Ring, M.D.
Assistant Professor of Surgery
Director, Heart Transplant Program
Univ. of Minn. Hospital and Clinic

Gayl Rogers, Rn, B.A.N.
Dir., Organ and Tissue Procurement
in Transplant Donor Services
American Red Cross

Margy Ross, R.N.
Educator
Unity Medical Center

Carol A. Tauer, Ph.D.
Professor of Philosophy
Department of Philosophy
College of St. Catherine

ADVISORY COMMITTEE

Mila Ann Aroskar, Ph.D.
Chair, Public Health Nursing
University of Minnesota

Nancy Ascher, M.D., Ph.D.
Asst. Prof., Dept. of Surgery
Univ. of Minn. Hospital & Clinic

Andrew P. Czajkowski,
President
Blue Cross / Blue Shield of
Minnesota

Frazier Eales, M.D.
Minnesota Thoracic Group, P.A.

Bernard Gersh, M.D.
Cardiovascular Surgeon
Mayo Clinic

David Graven, J.D.
Attorney,
Holmes & Graven

Ronald Hamel, Ph.D.
Professor of Theology
St. Thomas University

Thomas Jolicoeur
Supervisor
Professional Services Section
Minn. Dept. of Human Services

Daniel F. McInerney
Assistant Commissioner
Minnesota Department of Health

Laird Miller
Corporate Director
Health Services
Honeywell, Inc.

Evelyn Van Allen, M.P.H.
Coordinator
Minnesota Network of Institutional
Ethics Committees
Minnesota Hospital Association

Neal Vanselow, M.D.
Vice President of Health Services
University of Minnesota

SECTION 3

CITIZENS PANELS AND THE CENTER FOR NEW DEMOCRATIC PROCESSES

Introduction

The Center for New Democratic Processes is one of the oldest think tanks in America working full time on reforms of the democratic system. There are other organizations older than we which do research and development, and have agendas of reform; we are unique in our emphasis on both long term reflection and ongoing field testing. CNDP was founded in 1974 by Ned Crosby and a group of civic leaders in Minneapolis. It has included on its Advisory Council since its inception such prominent academics as Robert Dahl, the Yale political scientist; Paul Meehl, Regents professor of psychology at the University of Minnesota; and Guido Calabresi, currently dean of the Yale Law School.

Backed by a reliable source of funding over the years, we have been able to devote ourselves to fundamental research and development of a variety seldom done because of funding constraints. As a result, we have developed two new democratic processes and brought one of them to the point where it can be used to correct a fundamental problem of our current political system. The foundations of this work lie in six major field studies and numerous essays and internal reports in which the details of the new processes have been worked out.

The main process we have developed is a Citizens Panel, modeled on the jury system (we capitalize the term to differentiate it from other types of citizens committees). Citizens Panels are different from other citizen's groups, in that they are composed of randomly selected people, rather than the more common blue-ribbon panels or panels appointed to represent various interests. In 1984 we ran five regional Citizens Panels (culminating in one statewide Panel) on the question of agricultural impacts on water quality in Minnesota. This was the first use of the jury model on a public policy question in the United States which had the sponsorship of governmental agencies. In 1985 we learned that a team of social scientists in West Germany had developed a very similar process, which has been used with governmental sponsorship since 1978.

The immediate task of CNDP is to introduce Citizens Panels into the current political system. We believe they can have a profound effect on the workings of American democracy in the 1990s. This is an ambitious goal for a small organization, but the careful ground work we have done should enable us to succeed.

Why Citizens Panels?

The Western experiment with democracy over the last 200 years is one of great success. The standards of living and of education have made marvelous advances in that period. There are many accomplishments of which we in America should be very proud.

But at the moment of greatest material success our democratic system stands in considerable danger. A democracy cannot function properly when the public is unable to express its collective, considered opinion about the major issues of the day. At the very time that our problems are becoming more subtle and the solutions more complex, the tools for manipulating public opinion have become very sophisticated. Modern advertising and media techniques are becoming ever more powerful as they are combined with focus groups and public opinion polling. The result is that the "voice of the people" which seems loudest and clearest often represents the best financed point of view, rather than the conclusion which would likely be reached by an interested and informed citizenry. The "voice of the people", as it is expressed through the media, and as legislators experience it through letter-writing campaigns, is increasingly the voice of powerful, small groups. This leads to apathy toward the political system and mistrust of government by a majority of citizens. America, then, drifts along, with our basic problems untended, while those who understand the new tools of public relations (and can afford them) attempt to manipulate the public in one direction or another.

Citizens Panels are a democratic reform capable of correcting this situation. They have this power because they deal with some of the most basic problems of creating an informed public:

- It is exceedingly difficult to educate the public on a complex policy issue. Citizens Panels give an intense education on a specific issue to a group of people who are then asked to recommend what should be done.
- One of the great difficulties of getting educated citizen input on an issue is that inevitably those who take the time to become well informed are a small minority of the public. This leads to the standard charge that the average American does not share the views of the "vocal elite" which understands the situation. Citizens Panels, like a jury, draw their participants at random and pay them to participate. This means that they are a group of average Americans which in no way can be accused of being an elite.
- It is common today to assume that any group or new process is simply a way to promote the interests or ideology of some group. Citizens Panels are designed so as to make it very difficult for anyone to manipulate the results. Many of these safeguards are borrowed from the legal system and others are innovations which evolved out of a dozen years of practice.
- One of the difficulties of introducing innovations into the political arena is that the public may resist them because they seem so odd or radical. But juries are not seen as

either odd nor radical. Citizens Panels modeled on the jury system have many complex refinements, but the basic concept is very easy for the average citizen to understand.

CNDP Experience

Our initial work concentrated on research on Citizens Panels. In 1974 a randomly selected group of individuals designed a national health care program. In 1976 we experimented with a randomly selected committee to study the race between Carter and Ford. In 1981 the Presbytery of the Twin Cities Area commissioned us to convene a balanced panel of their members to study peacemaking over a four month period.

We have also run two Extended Policy Discussions to clarify disagreements between experts on a complex policy. In 1976-77 we ran a project on the question of grain reserves with U.S. Reps. Bob Bergland, Paul Findley, and Rick Nolan as sponsors. In 1977 several Minnesota legislators (Rep. Gary Laidig, Rep. Ken Nelson, and Sen. Gerry Sikorski) requested an Extended Policy Discussion on the question of serious juvenile offenders.

The major use of a Citizens Panel was in 1984 when we conducted a study of the impacts of agriculture on water quality in Minnesota. There were eleven sponsors for this project: the Association of Minnesota Counties, Center for Urban and Regional Affairs, Izaak Walton League of Minnesota, Minnesota Association of Soil and Water Conservation Districts, Minnesota Department of Agriculture, Minnesota Department of Natural Resources, Minnesota Farm Bureau, Minnesota Farmers Union, Minnesota Pollution Control Agency, Minnesota Sportfishing Congress, and the Minnesota Soil and Water Conservation Board. Five regional Citizens Panels were convened to determine the significance of the issue, the need to take action on it, and the amount to be spent. Then three members from each regional panel attended a statewide panel which put together recommendations about what should be done about the problem. These led to a variety of steps by the sponsors and contributed to some actions taken by the Minnesota Legislature. An article on this project appeared in the March/April 1986 issue of the Public Administration Review.

Office Organization and Staff

We are a staff of four professionals working in an office with an integrated computer system and minimal secretarial help. We have a Board of prominent Twin Cities residents of diverse points of view, with whom we work closely to shape our ideas and the directions our work will take. We use weekly staff meetings and a modified management by objective scheme to keep track of our activities. At the same time we leave ample time for the reflective work and the essays which are the foundation of our work on new democratic processes.

The staff of CNDP consists of two academic activists, a person skilled in public relations and legislative activities, and an administrator.

- Ned Crosby received his Ph.D. in political science from the University of Minnesota in 1973. In 1970 he worked with two others in Minnesota to set up one of the nation's first pre-trial diversion projects. In 1972 he was research director of Help Unsell the War, a project which ran award winning TV commercials against the bombing in Vietnam. This was the first national media project of the peace movement to use extensive market research to show the value of its commercials. He has served as full time director of CNDP since its inception, but has also been the President of the Board of the Minneapolis Legal Aid Society, served on the Board of the African American Institute in New York, and served as the chair of Minnesotans for SALT.
- Paul Schaefer received his Ph.D. from the University of Minnesota in 1976 in cultural anthropology. In his graduate field research, he studied the effects of missionary activity on a small Pacific island. As a farmer and rural resident, in 1976 he began studying and later became involved in efforts in rural Minnesota and Wisconsin to halt further development of electric power lines and a nuclear power plant. He was associate editor, from 1982-84, of the Anvil magazine, an alternative publication published in rural Millville, Mn., and The Bridge, (1978-82), a newspaper devoted to alternative energy and published in Wisconsin. He currently holds the position of Associate Director of the Center for New Democratic Processes.
- Bruce Miller is a graduate of the University of Minnesota at Morris in Political Science. From 1984 to 1986 he served as the Executive Director of the United Handicapped Federation. From 1977 to 1984 he was the Regional Coordinator for Planned Parenthood of Minnesota in an eighteen county rural area of Minnesota, based in Mankato. He has also worked as a community organizer with the Minnesota Public Interest Research Group (MPIRG), and as a research analyst with a regional office of the Minnesota Governor's Crime Commission. He currently serves on the Board of Directors of the Philanthropy Project, and as the Treasurer of the Board of Directors of the Cooperating Fund Drive.
- Judy Carpenter received a B.A. in Political Science from Stanford University in 1966. She worked in the New York City administrative offices of Project Head Start as that agency began. She organized a Vietnamese family sponsorship group in California in the mid-70s, and was the supervisor of Medicare Part A Claims in Kansas City in the late 70s. In the early 80s she was active in the development of a community-wide alcohol abuse awareness effort, and taught court-ordered rehabilitation classes for misdemeanor offenders.

DIRECTORS

Robert D. Coursen,
Consultant

Ned Crosby,
President, CNDP

Hank Fischer,
Public Affairs Consultant

Peter A. Heegaard,
Executive Vice President,
Norwest Bank Minneapolis

Sally Howard,
Dir., Health Sci. Public Relations,
University of Minnesota

James J. Lynskey,
Professor, Political Science,
Hamline University

Bobbi McAdoo,
Associate Professor,
Hamline University Law School

Jane Ferguson Otis,
Partner,
Evergreen Learning Inc.

Charles A. Slocum,
Executive Director,
Minnesota Business Partnership

Steven B. Swartz,
Organizational Consultant,
Hubler Swartz and Associates

ADVISORY COUNCIL

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Dean,
Yale University Law School

Robert A. Dahl,
Prof. Emeritus, Political Science,
Yale University

Peter C. Dienel,
Professor of Sociology,
Univ. of Wuppertal, West Germany

Donald M. Fraser,
Mayor,
Minneapolis

Bill Frenzel,
Member of Congress,
3rd District of Minnesota

Paul E. Meehl,
Professor of Psychology,
University of Minnesota

Phillipa Strum,
Professor of Political Science,
Brooklyn College

SECTION 4

FINDINGS AND RECOMMENDATIONS

The panelists were given two types of opportunities to express their views. With regard to the two main substantive issues, they were given a set of specific questions to which they were asked to respond. This is analogous to the way a jury operates. After that, they were given a chance to elaborate on their answers in their own words. The third main question was a procedural one and is something which they answered in their own words. The staff suggested minor wording changes on a few of the questions; the panelists reviewed these, accepted some of them, and gave final approval to what follows.

REQUIRED REQUEST

The charge to the Panel was as follows:

Given current and increasing shortages of donor organs in Minnesota, would a Minnesota State Law on Required Requests be a good way to increase the supply of donor organs?

This charge was spelled out in terms of three specific questions, plus one in which they were asked to elaborate on their views. These questions are listed below, together with the answers which the Panel gave.

1. Agree upon the four things you like best about the idea of required request. After you have agreed upon four, rank them in their order of importance.

votes

- 22 It would increase the number of organs available for transplantation.
- 13 It would establish accountability and guidelines and would improve the training of the medical personnel who approach bereaved families.
- 12 It would give bereaved families the opportunity to consider an option they may not have thought of previously and therefore to have a sense of something positive in the midst of their sorrow.
- 11 It could result in eventual reduction of medical costs.

2. Agree upon the four things you like least about the idea of required request. After you have agreed on four, rank them in their order of importance

votes

- 17 If required request were handled badly, it would leave a negative image of transplants and could add to the stress on next of kin.
- 15 State legislation would be unnecessary in light of federal law; public awareness and education may be enough.
- 11 Required request could lead to the depersonalization of organ donation.
- 9 Required request may increase procurement costs because the organs would still need to be obtained on an individual basis.

*** Notice to the medical profession when talking to the public: Discontinue the use of the words "harvesting organs" and "viable recipients."

3. The subject of required request was discussed at some length before the Citizens Panel.

A. Based on the testimony you have heard, would you want Minnesota to implement required request or not?

16 YES

8 NO

B. In general, how do you feel about hospitals in Minnesota having to follow such guidelines?

13 Strongly approve.

9 Approve

0 Unsure, don't know

1 Disapprove

1 Strongly disapprove

4. Now that you have given answers to the above questions, you have the opportunity to elaborate on the charge and suggest alternate means of increasing donor organs. (Staff note: The panelists responded to this by concentrating on alternative means of increasing donor organs. These are listed in their order of popularity.)

votes

- 21 Increase public education on what constitutes a donor and on how to facilitate the donation process.
- 17 There should be an investigation of the procedures of those hospitals which currently have a high success ratio of obtaining donor organs. This investigation should be state funded and therefore available to everyone.
- 14 Implement a hospital inquiry policy at the time of admission to be followed up if something adverse happens to the patient.
- 9 Validate the present donor card system, possibly through legislation which would strengthen the legality of the donor's wishes.
- 9 There should be positive press coverage on transplants and organ donation.

INDIVIDUAL-ORIENTED VERSUS POPULATION-ORIENTED PROGRAMS

The charge to the Panel was as follows:

What is an appropriate distribution of available health care resources between individual-oriented programs such as heart transplants and population-oriented programs such as public education about the health risks of tobacco use?

This charge was spelled out in terms of seven specific questions, plus one in which they were asked to elaborate on their views. These questions are listed below, together with the answers which the Panel gave.

- 1. In general, how do you presently feel about more available funds being spent on individual-oriented programs, such as heart transplants?

| | |
|----------------------|-----------------------|
| 12 Strongly approve. | 1 Disapprove |
| 11 Approve | 0 Strongly disapprove |

2. Agree upon up to four sources of additional funding for individual-oriented programs, such as organ transplants. Rank these in the order of priority, placing a 1 next to the source you prefer the most, etc.

votes

- 22 All health insurance coverage must include transplants; in addition, insurance companies should contribute to insurance pools for uninsured individuals.
- 17 Government funding (similar to that for kidney programs).
- 17 Stop tobacco subsidies and use the funds for transplants (Note: the Panel feels very strongly about this recommendation).
- 15 Increase the cigarette tax and use the additional funding for transplants.

3. In general, how do you feel about more available funds being spent on population-oriented programs, such as public education about the health risks of tobacco use?

| | |
|---------------------|-----------------------|
| 3 Strongly approve. | 5 Disapprove |
| 9 Approve | 1 Strongly disapprove |
| 5 Neutral | |

4. Agree upon up to four sources of additional funding for population-oriented programs, such as public education about the health risks of tobacco use. Rank these in the order of priority.

votes

- 21 Increase taxes on tobacco, liquor, etc.
- 17 Government funding without tax increases.
- 16 Corporations, foundation and private donations.
- 13 Stop subsidizing the tobacco industry.

* Highlight: The Panel also recommends that private corporations provide funding for health education programs for employees.

5. If \$100 million were suddenly available from some source, acceptable to you, and the money had to be divided between individual- and population-oriented programs, how would you divide that money?

\$ 75 million to individual-oriented programs

\$ 25 million to population-oriented programs

6. If \$100 million suddenly had to be taken away from either individual-oriented programs or population-oriented programs, how would you divide that money?

\$ 30 million from individual-oriented programs

\$ 70 million from population-oriented programs

7. If \$100 million were suddenly available from some source, acceptable to you, how would you allocate this money?

\$ 20 million to individual-oriented health care programs

\$ 5 million to population-oriented health care programs

\$ 75 million to other programs
(Minnesota government programs)

At this point the Panel was given the opportunity to elaborate on the charge. Their decision was to discuss alternatives to the emphasis on heart transplants as an individual treatment and smoking prevention as a population-oriented program. The following programs, in no particular order, were viewed as important:

Individual programs:

- Treatment program for AIDS patients
- Expansion of hospital alternatives, such as hospice or home care programs
- Elderly care
- Health care for the indigent population
- Drug and alcohol rehabilitation
- Mental health care

Population programs:

- AIDS research and prevention
- Teenage pregnancy and sex education
- Preventive Medicine
- More emphasis on environmental policies (such as Clean Indoor Air Act)
- Increased education about mental health resources
- Family crisis centers

QUESTIONS FOR STATEWIDE CITIZENS PANEL ON HEALTH PROGRAMS

The charge to the Panel was as follows:

Which health care question(s), in addition to the discussed questions on organ transplantation, should a statewide panel consider?

The Panel was asked to list, in order of priority, several health care questions which they felt would be appropriate for consideration by future Citizens Panels, including a statewide Citizens Panel in 1987.

1. How should the high cost of AIDS treatment be handled by society, and what is the effectiveness of public education programs on the prevention of AIDS?
2. How can we provide affordable and safe health care for the elderly?
3. How can education in family/social responsibilities impact preventive health care?
4. Why are health care costs so high, and how can we lower them?
5. How can we better control drug and alcohol abuse?
6. What measures are necessary to provide physical and mental health care for the homeless?
7. What environmental policies could be implemented to promote better health in general, and how should they be administered?
8. What are the possible solutions to the cost and care of teenage pregnancy?

*** The Panel also indicated that the topic of organ transplants had a priority of 4 - 5 in the above list.

SUMMARY OF TESTIMONY ON RESOURCE UTILIZATION

The Citizens Panel on Transplants and Public Policy heard testimony from four individuals on the subject of appropriate distribution of available health care resources between individual-oriented programs such as heart transplants and population oriented programs such as anti-smoking education:

- W. Steves Ring, M.D.
Director, Heart Transplant Program
Associate Professor of Surgery
Division of Cardiovascular and Thoracic Surgery
University of Minnesota Hospitals
- Thomas Kottke, M.D.
Assistant Professor of Medicine and Public Health
University of Minnesota Hospitals and Clinic
- Kathleen Daly, M.P.H.
Epidemiologist
Minnesota Department of Health
- Craig Ayers J.D. (Transplant Recipient)
Assistant State Negotiator
Department of Employee Relations

The four witnesses concentrated on different aspects of the question before the panel. Ring and Ayers concentrated on information related to heart transplants while Kottke and Daly concentrated more on public health and education programs. As a result there were few items where all four witnesses clearly agreed or disagreed with one another.

Each witness was given 45 minutes to make a presentation and field questions. This was followed by a 15 minute summary in the morning and afternoon.

Areas of Agreement and Disagreement

1. Ring and Kottke stated that individual-oriented programs and population oriented programs are not mutually exclusive.
 - A. Both transplant programs and public health programs such as anti-smoking education are important. We can and should have both.
 - B. Ring and Kottke agreed that the savings in health care costs that could result from effective public initiatives aimed at changing personal habits could pay for the nation's organ transplant programs. One problem is the time lag involved in reaping obvious economic benefits from public education efforts.

- C. Kottke estimates that a 5% reduction in the Minnesota smoking rate would save enough money in health care costs to pay for the heart transplant and 10 year maintenance costs for 80 heart transplant recipients, the expected annual number.
- 2. Daly stated that we do need to decide whether to put more money into individual-oriented programs or into population-oriented programs.
 - A. Daly favors spending more money for the population-oriented programs. She described them as being largely preventative in nature and that it is much cheaper and more effective to prevent disease than simply to treat people once they have the disease.
 - B. Daly estimated the cost of Minnesota's 80 annual heart transplants at \$6 million, figuring \$75,000 per transplant. She estimates a public awareness project against smoking in Minnesota, targeted at school kids and smoking adults could convince 2% of them not to smoke. With a target audience of 1,740,000 people, this would mean 37,000 people would have a very positive and important health benefit with program costs of only \$57 per person.
 - 3. Daly and Ayers disagreed on the effectiveness of public education efforts concerning smoking, organ donation and other health issues.
 - A. Daly testified that public education in the area of health is beneficial and cost effective. She pointed out that smoking rates began to drop about the same time the Surgeon General started to actively inform the American public about the dangers of smoking. She also pointed out that seat belt usage was very dependent upon public education efforts.
 - B. Ayers testified that he was skeptical of the effectiveness of public education efforts. He thought it was OK to spend some money on such programs, but questioned spending a great deal in that area.
 - 4. Ayers claimed that most of the costs associated with transplants are actually "substitution" costs. These costs reflect money that would have been spent anyway on the long term hospitalization costs people would incur as they slowly died or were maintained if they did not receive an organ transplant.

- A. Charges for intensive care can be over \$1000 per day. Ayers' hospital costs in 1984 were \$500 per day. If he had not received his transplant but had instead been in the hospital for the six months he potentially had remaining, his hospital bill would have been \$84,000. He sees his transplant as an up front cost bargain.

Other Important Points

1. Both Ring and Ayers stated that transplant programs are a very small percentage of the US health care system cost.
 - A. Ring said that transplant programs reflect less than one percent of U.S. health care costs.
 - B. Ayers noted that transplant costs were very small compared to the tremendous costs of other public expenditures such as AIDS victim care, public access for the handicapped, and work place safety.
2. Ring and Ayers testified that the numbers and rate of success for transplants has grown tremendously over the last few years.
 - A. Ring said there had been only one death at the U of M heart transplant center in the past year, out of 40 transplants. They are getting a 95% survival rate after first year, 80% after five years.
 - B. An increasing number of heart recipients are leading quite active lives, including regular sports activity.
3. Both Ring and Ayer stated that the inability to pay for a transplant on the part of the recipient is a major problem with the current organ procurement system. Both stated that something will have to be done about this problem. This may involve more public expenditure.
4. Kottke and Daly both testified that personal habits are a very large factor in American health care costs.
 - A. Kottke stated that 60% of our national disease burden is caused by a few habits such as poor diet, smoking, lack of exercise, poor oral hygiene, nonuse of seat belts and handguns.
 - B. Smoking, hypertension and high cholesterol diet, all modifiable items, are the three main risk factors of coronary heart disease.

- C. 50% of the U.S. population has above ideal cholesterol levels in their blood. One third of the U.S. smokes.
 - D. Kottke stated that 11% of all deaths in Minnesota are attributable to smoking. (Daly stated 5%) Kottke also said 15% of all disability in Minnesota is attributable to smoking.
 - E. Smokers use more sick leave and use up more health benefits than do non smokers in Minnesota.
 - F. Daly stated there are 170,000 smoking related cardiovascular deaths every year in the USA.
 - G. Daly stated that general population health studies show that if 5% of the population contracts or dies from a disease, 10 - 20% of the smoking population will contract the disease or die from it.
 - H. Kottke stated that Minnesota currently has 20,000 deaths per year due to coronary heart disease. Close to half of these cases are preventable along with the high costs associated with them.
5. Kottke cited a major study in Finland which showed that only modest change in the population's personal habits was sufficient to cut mortality from coronary heart disease by 25%.
6. Kottke stated that when we think about health care costs we should remember that we actually subsidize smoking through increased health insurance premiums, federal, state, and local health care expenditures, sick leave benefits and government aid to tobacco farmers.
7. Kottke argued that we can decrease mortality attributable to coronary heart disease most effectively if we work with the general population rather than primarily with the high risk population.
- A. The deaths of high risk people are a low percentage of total coronary heart disease deaths. The great majority the U.S. population and deaths are in the middle levels of risk, not high risk.
 - B. If we were to eliminate all deaths in the high risk group we would only decrease coronary heart disease deaths by 10%. If we instead decrease everybody's cholesterol by a relatively modest amount we would have then cut mortality by 30%.

8. Both Daly and Kottke testified that social expectations were the single most important factor in people's smoking habits. Daly and Kottke both said that it is important to have public awareness programs in order to change social expectations so that people will simply reject smoking as a negative thing.
9. Daly testified that long term studies of smokers, nonsmokers and people who have quit smoking show that within five to ten years after quitting, exsmokers coronary heart disease risk level dropped to that of the nonsmokers. Daly said this is evidence of the great health benefit and health care cost saving that can result from efforts to decrease smoking.
10. Craig Ayers stated that there is a natural limit of about 1300 transplantable hearts that will be available every year in the USA. He termed this as a cap on the size of the US heart transplant program, and therefore a built in limit on the costs of heart transplant activities in the USA.
11. Ayers testified that if the public does not contribute anything to heart transplant programs in the USA there will still be many heart transplants, but only the wealthy will have them.
12. Ayers claimed that if the U.S. government were to pay for all heart transplants (something he does not recommend) the cost to the U.S. taxpayers would be \$50 million dollars per year. He noted that this figure was only one fifth the size of the recent Minnesota Income Tax cut.
13. Ayers said if we do not have programs to provide heart transplants the USA stands to lose all the wealth that would have been generated by living recipients. that if we use a wealth creation ratio of three to one, meaning if a person receives a salary of x, he or she will produce 3x amount of goods or services, then 1300 annual heart transplant recipients back working on their jobs would create 500 million dollars in new wealth every year.

APPENDIX A
 SELECTING PARTICIPANTS
 for the
 CITIZENS PANEL ON TRANSPLANT POLICY

General Comments:

The process of selecting participants for a Citizens Panel is a two-step process. First, a group of individuals is selected at random in such a way that they represent the public at large in terms of sex, education, and age. This pool should be about eight times as large as the number of participants and alternates needed. From this pool we approach those who say that they "probably" or "might" be willing to participate in the Panel and who were willing to give us their names and addresses.

Our aim is to select a Panel which is balanced on an attitude which is relevant to the question at hand. We do not try, however, to balance the Panel on sex, age, and education. This is analogous to the way in which a jury in the legal system is put together: the pool from which the jurors are drawn should be a cross section of the community, but no attempt is made to balance the jury itself in terms of age, sex, etc. On the other hand, a process called "voir dire" is used in which the opposing attorneys can eliminate jurors who may have a preconceived view about the outcome of the case. We do not use the "voir dire" process with Citizens Panels, in large part because it is very difficult to say which views on public policy issues are inappropriate. Instead, we balance the Panel so that its views correspond to the views of the community on an attitude relevant to the issue under study.

In the survey data below, the responses of the original 24 panelists and 5 alternates are combined. On its convening day, the panel will be composed of 24 of these 29 people.

In this project, there was no good recent survey data from Minnesota on attitudes regarding transplant policy, so we used a standard question on political views, taken from the Northstar Poll. In this way we can be sure that there is the same proportion of conservatives, liberals, and moderates on the Panel as there is in the Metro Area. The political views of the panelists and of those living in the Metro Area is shown below:

| | Panel | Metro Area |
|--------------------|-------|------------|
| Conservative | 35% | 33% |
| Middle of the Road | 42% | 43% |
| Liberal | 24% | 24% |

Steps in the Selection Process

1. Randomly select numbers from the November, 1985, Minneapolis Telephone Book.
 - A. Determine the sample size and number of phone numbers needed. Previous experience has shown us that roughly 16 times as many names need to be selected as the size of the Panel. In our case we needed 30 people who would agree to serve (24 participants and 6 alternates). Hence, we decided to select an initial pool of 500 numbers to be called.
 - B. Determine what pages to be selected from the Minneapolis Phone Book (which begins on p 35). We discovered that the way to cover the 1761 pages of the book was to count off every 3rd and then every 4th page. Therefore, we randomly picked a starting point between pp35-37 and counted off every 3rd, followed by every 4th page. The result was a total of 503 numbers to be called.
 - C. We then used a table of random numbers to select a column on each page. The instructions we used to pick a number in the column were as follows:
 - a. Use a table of random numbers, and pick a place at random to start. Use the first two integers in that number to indicate the position in the column to select.
 - b. If the number is close to 100, it may be necessary to continue counting off names in the next column or even to continue to the next page.
 - c. If the name selected is a business, continue to the next residential number. Again, it may be necessary to continue to the next column or to the beginning of the first column on the next page.
 - d. In counting down the column, count only those entries not indented and do not count headings with no number.
2. Select those to be interviewed for the survey
 - A. The 503 names selected above were entered on the face sheets of the questionnaire, along with their random number, phone numbers, and addresses. We then randomized the list again so that those from the end of the alphabet were as likely to be chosen as those from the beginning.
 - B. Our target number for completed interviews was to have 115 people who say that participation in our project is possible (ie, who answered "probably" or "might" to the question about whether or not they would want to participate). We then used a stratified sampling procedure so that the pool of 115 would match the general public in the area on age, sex, and education. In fact, we ended up with a pool of 122 people who possibly would participate in the Panel.

3. Select participants for the Panel

- A. The 122 "possibles" were again randomized so that we would be as likely to extend invitations to those interviewed last as to those interviewed first.
- B. From the pool of 122 potential participants, we selected the top half of the names on the list and sent them letters.
- C. We then called and set up appointments with as many as possible of those on the lists who have been sent a letter. Our aim was a Panel of 24 people who are balanced on their political views. This means that 33% (8) of them should be conservative, 43% (10) of them middle of the road, and 24% (6) of them liberal. (For alternates, we decided to pick 2 conservatives, 2 middle of the road, and 1 liberal.) This meant that once we reached the quota (including alternates) in any one category, then we stopped the selection in that category and concentrated on the other two.

Results of the Survey

The following results were obtained from the survey we conducted in the beginning of October, 1986. It is important to remember that the sample size was too small to make inferences about the attitudes of the population living in the area covered by the Minneapolis phone book. By completing 179 interviews, we contacted enough people to find the participants needed for our project, but not nearly enough to make reliable estimates about the views of those living in the area. For that purpose at least 600 interviews would have been necessary.

The following is a breakdown of what happened with the 503 names drawn from the Minneapolis phone book:

| | <u>number</u> | <u>percent</u> |
|-----------------------------------|---------------|----------------|
| Not contacted because quotas met | 28 | 5% |
| Phone disconnected or business | 54 | 11% |
| No answer; Incompleted call-backs | 69 | 14% |
| Refused to be interviewed | 96 | 19% |
| Ruled out because of age/sex | 77 | 15% |
| Completed interviews | 179 | 36% |
| Total names drawn | 503 | 100% |

The survey questions, their results, and a comparison to relevant polling and census data, are as follows:

1. First, I'd like to ask a question about health care in America. Which of the following statements comes closest to expressing your overall view of the American health care system?

| | Panel | Survey | National* |
|---|-------|--------|-----------|
| A. On the whole, the health care system works pretty well, and only minor changes are necessary to make it work better. | 38% | 31% | 26% |
| B. There are some good things in our health care system, but fundamental changes are needed to make it work better. | 52% | 55% | 49% |
| C. The American health care system has so much wrong with it that we need to completely rebuild it. | 10% | 13% | 21% |

* Source: Survey done by Louis Harris & Assts. for the Kaiser Family Foundation in Aug.-Oct., 1984. Cited in Public Opinion, Aug./Sept., 1985.

2. Do you believe the government should pay for artificial heart implants and other expensive medical procedures for those who need financial assistance?

| | Panel | Survey | Metro* |
|---------------|-------------|-------------|------------|
| A. Yes | 62% | 52% | 59% |
| B. No | 14% | 27% | 28% |
| C. Don't know | 24% | 21% | 13% |
| | <u>100%</u> | <u>100%</u> | <u>98%</u> |

* Source: Survey reported by Northstar Poll on May 13, 1985.

3. Here are two approaches to health and sickness: one approach -- treatment -- which seeks to cure sickness, and another approach -- prevention -- which seeks to prevent sickness. At the moment, do you think the health care services in your area have got the right balance between treatment and prevention or should we be giving more emphasis to treatment or prevention?

| | Panel | Survey | National* |
|---|-------------|-------------|------------|
| A. Got the right balance. | 17% | 22% | 23% |
| B. Should give more emphasis to treatment. | 7% | 5% | 10% |
| C. Should give more emphasis to prevention. | 66% | 60% | 52% |
| D. Don't know, other | 10% | 13% | 3% |
| | <u>100%</u> | <u>100%</u> | <u>88%</u> |

* Source: Survey by Louis Harris for Prevention magazine, November, 1984; Citation: Public Opinion, August/September 1985, p. 60/

4. Would you please tell me in what age category you fall?

| | Panel | Survey | Metro* |
|-----------------|------------|------------|------------|
| A. 18 to 24 | 17% | 8% | 20% |
| B. 25 to 34 | 31% | 30% | 25% |
| C. 35 to 44 | 14% | 19% | 16% |
| D. 45 to 54 | 10% | 14% | 13% |
| E. 55 to 64 | 10% | 12% | 12% |
| F. 65 and over. | <u>17%</u> | <u>17%</u> | <u>14%</u> |
| | 99% | 100% | 100% |

* Source: 1980 Census Data.

5. In terms of your political outlook, do you usually think of yourself as: (START WITH "VERY CONSERVATIVE" ONCE, THEN "VERY LIBERAL" NEXT TIME.)

| | Panel | Survey | Metro* |
|-----------------------|------------|------------|------------|
| A. Conservative | 34% | 31% | 33% |
| B. Middle of the road | 41% | 45% | 43% |
| C. Liberal | <u>24%</u> | <u>23%</u> | <u>24%</u> |
| | 99% | 99% | 100% |

* Source: 1980 Census Data.

6. What's the last grade you attended in school?
(DO NOT READ LIST!)

| | Panel | Survey | Metro* |
|-----------------------------|------------|------------|------------|
| A. Less than high school | 10% | 6% | 18% |
| B. High School graduate | 21% | 29% | 37% |
| C. Some college or vo-tech | 45% | 35% | 23% |
| D. College graduate or more | <u>24%</u> | <u>31%</u> | <u>22%</u> |
| | 100% | 101% | 100% |

* Source: 1980 Census Data.

7. RECORD SEX

| | Panel | Survey | Metro* |
|-----------|------------|------------|------------|
| A. Female | 48% | 53% | 52% |
| B. Male | <u>52%</u> | <u>47%</u> | <u>48%</u> |
| | 100% | 100% | 100% |

* Source: 1980 Census Data.

8. After this survey is completed, we will be randomly selecting people to serve on a panel like a jury. This panel will study some health care questions we face here in Minnesota and will make a report to a blue ribbon committee of health professionals. Those who participate will be paid \$75 a day for their services. Is this something which you ...

| | Panel | Survey |
|---|------------|------------|
| A. Would probably want to do? | 69% | 20% |
| B. Would probably not want to do? .. or | 0 | 32% |
| C. Might want to do? | <u>31%</u> | <u>48%</u> |
| | 100% | 100% |

APPENDIX B

SUMMARY OF TESTIMONY ON REQUIRED REQUEST

The Citizens Panel on Transplants and Public Policy heard testimony from four individuals on the subject of required request:

- Margy Ross, R.N. (transplant recipient)
Educator
Unity Medical Center
- Robert C. Anderson M.D.
Chief, Kidney Transplant Program
Department of Surgery, Hennepin County Medical Center
- Sandra Griffin R.N.
Staff Nurse
Transplant Section, University of Minnesota Hospitals
- Gayl Rogers R.N., B.A.N.
Director, Organ and Tissue Procurement,
Transplant

The following is a summary of the major points of agreement and disagreement between the witnesses. Each witness was given 45 minutes to make a presentation and field questions. This was followed by a 15 minute summary in the morning and afternoon. The result was 3 1/2 hours of taped material, upon which the following is based.

Areas of General Agreement

1. There is a need for transplants and therefore for organ procurement.
 - A. Dialysis is not a solution to kidney failure. Dialysis is often debilitating and in the long run more expensive than a transplant. For people on long term dialysis life is frequently not worth living due to weakness and discomfort.
 - B. Patients often die waiting for a transplant, i.e. a transplant was their only hope for survival.
2. We need more organs for transplantation.
 - A. There are long lists of people waiting for organs. In Minnesota there are usually 250 people on waiting list for kidneys. Nation wide there are usually 10-12,000 waiting for kidneys, 100 or more for hearts, and 300 for livers.
 - B. The number of transplant operations of all kinds is growing rapidly. Just in the last few years the number of heart transplant programs in the USA has grown from a few to over 130.
 - C. Dr. Ring, in other testimony, said that of those in 1985 qualified for heart transplants at the University of Minnesota, 25% died while waiting for an organ donation.

- D. In the USA, only 10-15% of all possible donor organs are actually retrieved from brain dead individuals.
 - E. Timing is also an important factor in transplants and organ availability. Often a patient will need a transplant within a very short period of time. If no appropriate donor is found quickly, the patient may die.
3. The system of having potential donors identified through a donor card or on the driver's license is not an adequate solution to the organ donor shortage, but it is helpful.
- A. Often the licence or card is not found by the hospital staff at the time a potential donor is brought in. (There were several questions from the Panel about why this could not be changed.)
 - B. Nevertheless, the fact of having it on the license is a good idea. It is an essential part of public education and often leads families to discuss the topic of organ donation for the first time in a serious way.
 - C. If the hospital does see a card or license notation it does give them the signal to take measures to preserve the organs of a potential donor even before the family has been approached.
4. It is necessary to approach the family of the potential organ donor.
- A. This is an important step, since many potential donors have never indicated on their licence, or in any other way, that they wish to be donors.
 - B. Even if the system of indicating the wish to donate organs is perfected, it would still be vital to approach the families. First, there are some very complex legal and moral questions about whether someone can stipulate in advance that they want to be a donor and that their family has no rights to contravene this decision. Second, as a practical matter, it is essential to keep the families of donors supportive of the choice which was made. Public education and good will is an essential element in a successful donor program.
5. Approaching the family of a potential organ donor must be done with extreme sensitivity.
- A. This sensitivity is vital for maintaining public support for transplant programs.

- B. The family has been shattered by the death, it is a time of great stress and grief.
 - C. The person asking families about possible organ donation must be carefully trained, must feel comfortable about donation, must understand the grieving process, and must use extreme sensitivity.
 - D. According to a study done in Chicago, a family's response to an organ donation request depends almost entirely on the comfort level of the person actually making the request. 84% of the families in the study who were approached by a confident nurse said yes. 100% of those families approached by an uncomfortable nurse refused to donate.
6. Organ donation can be a very positive development for the family of the donor.
- A. Being able to do something positive for someone else is usually a positive development for a family in the midst of tremendous grief. Often the family will receive information later about how the organ receiver has fared. Knowing that the death of their loved one somehow made it possible for somebody else to live makes things better for the family in the days and weeks after the death.

Areas of Disagreement

Generally, Ms. Ross, Ms. Griffin, and Ms. Rogers were supportive of Required Request legislation. Dr. Anderson was not. Below is an outline of the major points pro and con Required Request gathered from the testimony of all four witnesses.

1. Arguments in favor of Required Request

- A. At the time of a person's death, their family needs to be reminded of any opportunity for organ donorship. It is a time of high stress and grief, a time when it is highly unlikely that the family will think to ask about organ donor opportunities.
- B. States where Required Request laws have been enacted have seen marked increases in organ donations, sometimes doubling or tripling the number of certain types of donated organs.
- C. Families may indeed regret the fact that they were not asked and did not think of organ donation. This regret can cause the family problems in the long run. Required Request would help families avoid this problem.

- D. Lack of public awareness is the key reason for the shortfall in organ donations, not public acceptance of donation. In surveys people usually give supportive reactions to the concept of donation. When actually approached at the time of a death, 90% of families agree to donation. The problem then is not attitude, it is that people are not asked and do not know of the opportunity.
- E. It is very rare for a family to regret saying yes to organ donation.
- F. Required Request will encourage increased awareness of transplant programs and opportunities among the health care community. This will in turn increase donor numbers as more health professionals know more about how to be aware of potential donors.
- G. Minnesota is a national center for transplants. Since February 24 states have adopted Required Request laws, increasing the numbers of donated organs. Due to the importance of organ transplant programs to the Minnesota economy and health care system, it is incumbent upon us to have our own Required Request law.
- H. Required Request is the responsible way to proceed because we should do our utmost to honor the requests of the dying person. By refusing to ask the family about donation we are maybe losing an opportunity to respect these wishes.
- I. Asking a family about organ donation is one of the rare opportunities for them to be in control. Usually up to that point they have simply been forced to leave all the important decisions up to the health professionals.
- J. By failing to ask the family about organ donation the hospital staff is implicitly making the decision for them.
- K. Representative Kahn, from the audience, stated that she views Required Request as simply a reenforcement of common courtesy, much like the Minnesota Clean Indoor Air Act. She said she thought many hospital administrators would like Required Request because it will back them up in their desire to approach people about much needed organ donorship.

2. Arguments Against Required Request

- A. The number of donated organs is increasing rapidly in Minnesota without Required Request. Proponents of Required Request point to increases in donations of 50 to 100% in several states with new Required Request laws. But at the kidney transplant program at the Hennepin County Medical Center the increase in donations from 1985 to 1986 is likely to be about 70%. This is probably due to increases in public awareness and trust. There is no good evidence that this rate would have been higher if Minnesota had had a Required Request law.
- B. There is a real danger that under Required Request health care professionals who are themselves opposed to organ donation, or who are very uncomfortable with it, will be forced to ask families about organ donation. This will lead to negative and insensitive approaches, bringing harm to the delicate transplant programs. Positive public opinion and good will are vital to all transplant programs. Bad rumors about donation requests have spread in the past, and will spread again under required request.
- C. Only about 1% of all people dying in a hospital are potential donors. A donor must be brain dead, have no history of hepatitis, cancer, IV drug abuse, homosexuality, AIDS, or major disease or infection.
- D. Potential donors must die in a hospital with a neurosurgeon or neurologist competent to pronounce brain death. This mandates having machinery for brain scans. Many rural hospitals will be in a difficult situation under Required Request due to lack of particular specialists or equipment.
- E. Organ donation should be based upon prior information on the part of the family and a signed donor card.
- F. A Required Request law without punitive measures may be ignored by those opposed to it. The only way to force people to follow a Required Request law will be through a massive system of investigation, which would be cumbersome and expensive.
- G. The number of donors will increase with the increasing number of transplants. This is due to the increased good public relations obtained by having more successful transplant receivers out in the community living among and talking with friends, family, and others.

Areas in Question

1. Gayl Rogers stated that Required Referral and Routine Inquiry are both possible alternatives to Required Request.
 - A. Under Required Referral all hospitals would be required to refer all cases of potential donors to a donor procurement agency. The agency would then approach the family to ask about organ donation. Rogers said the biggest drawback to this would be that agency people would have to come to a case cold, from the outside.
 - B. Under Routine Inquiry all hospitals would be required to ask a family if they wanted to talk to someone about organ donorship. If the family was interested in talking, then the procurement agency would be contacted and an agency staff person would come to discuss the matter with the family.
2. Representative Kahn stated that her understanding was that either of these two options, Required Referral or Routine Inquiry, would satisfy the requirements of her Required Request Bill.
3. Some witnesses mentioned that they were opposed to any punitive measures in a Required Request law because it would be unnecessary and be received negatively. These witnesses thought the medical profession would adhere to the law without any pressure from possible penalties. In addition there are hospital accreditation organizations that would typically monitor compliance with laws such as Required Request. Dr. Anderson, however, said that he opposes Required Request in part because of the extensive policing he believes would have to be done.

Other Points Made by Witnesses, Panel Members and Visitors

1. Nobody should donate organs against their wishes.
2. There is no body mutilation or pain for donor.
3. Organs can only be taken from brain dead individuals. People in a persistent vegetative state are not potential donors. There is no chance that doctors will give up early on someone because they are a potential donor.
4. There may be some problems with Required Request in rural areas. Hospitals may not have trained people. Small town doctors may worry about losing their autonomy.

5. Panelists were interested in ways to increase the usefulness of donor cards and driver license notations. It was suggested that hospitals could inquire about these items at the time of admission.
6. Another suggestion was to have the state instruct people to talk with their families about donorship wishes. Perhaps two family members could sign a donor card as witnesses.
7. The federal government passed PL 99-509 in July of this year. This law mandates that any hospital which participates in Medicaid or Medicare must establish formal procedures in order to encourage organ donation. Representative Kahn stated that her Required Request bill does not contradict this new federal law, but compliments it by setting up details of the program to encourage donors.
8. Representative Kahn pointed out that under her bill, the person approaching the family about organ donation cannot be anybody involved in the pronouncement of brain death. In other words the family doctor would not be the person doing the asking.
9. In responding to a panelist, Representative Kahn stated that as of yet nobody has studied the state by state results of Required Request laws in order to know what laws are producing the highest increases in donors. The panelist thought this information would be very helpful in determining what is best placed in any Minnesota law.

APPENDIX C

AGENDA

8:30 AM - 4:30 PM, November 13, 14, 15 and November 21 & 22, 1986

West Community Room
Edina Community Center - Third Floor
5701 Normandale Road South
Edina, Minnesota

DAY-BY-DAY AGENDA:

Day 1; Thursday, November 13 - Morning

- A. 8:30 Introductions
- B. 9:15 Introductions to Process and Citizens Panels
- C. 9:20 Questionnaire
- D. 9:25 Questions & Answers
- E. 9:55 Break
- F. 10:10 Introduction to bioethics and public policy
Carol A. Tauer Ph.D,
- G. 11:15 Break
- H. 11:30 Full Group Discussion
- I. 12:00 Lunch

Day 1; Thursday, November 13 - Afternoon

- A. 1:00 Introduction to "Charge" by staff.
Hand out summaries.
- B. 1:30 Video: the Lamm-Siegler debate
- C. 2:30 Break
- D. 3:00 Values Clarification process for panelists
- E. 4:15 Review

Day 2; Friday, November 14 - Morning

- A. 8:30 An overview of Question One
- B. 8:45 Witness, Required Request Legislation
Margy Ross, R.N. (transplant recipient)
- C. 9:30 Break
- D. 9:45 Witness, Required Request Legislation
Robert C. Anderson M.D.
- E. 10:30 Witness summation
- F. 10:45 Break
- G. 11:00 Small group discussions
- H. 11:30 Review
- I. 11:45 Lunch

Day 2; Friday, November 14 - Afternoon

- A. 1:00 Witness, Required Request Legislation
Sandra Griffin R.N.
- B. 1:45 Break
- C. 2:00 Witness, Required Request Legislation
Gayl Rogers R.N., B.A.N.
- D. 2:45 Witness summations
- E. 3:00 Break
- F. 3:15 Small group discussion
- G. 3:45 Overview of charge, small group deliberations, and
preliminary small group decision on question

Day 3; Saturday, November 15 - Morning

- A. 8:30 An overview of individual-oriented vs. population-
oriented programs.
- B. 8:45 Witness in favor of utilizing more resources for
individual-oriented programs
W. Steves Ring, M.D.
- C. 9:30 Break
- D. 9:45 Witness in favor of utilizing more resources for
population-oriented programs
Thomas Kottke, M.D.
- E. 10:30 Witness summations
- F. 10:45 Break
- G. 11:00 Small group discussion
- H. 11:30 Review
- I. 11:45 Lunch

Day 3; Saturday, November 15 - Afternoon

- A. 1:00 Witness in favor of utilizing more resources for
population-oriented programs
Kathleen Daly, M.P.H.
- B. 1:45 Break
- C. 2:00 Witness in favor of utilizing more resources for
individual-oriented programs
Craig Ayers J.D. (transplant recipient)
- D. 2:45 Witness summations
- E. 3:00 Break
- F. 3:15 Small group discussion
- G. 3:45 Overview of charge, and small group deliberations,
and preliminary small group decision on question

Day 4; Friday, November 21 - Morning

- A. 8:30 Selection of Panel Chair
Decision about small groups
- B. 8:45 Review of Charge to Panel: Required Request
- C. 9:00 Small group discussion:
 - 1) Response to a specific charge
- D. 9:45 Full group decision on specific charge.
- E. 10:15 Break
- F. 10:35 Small group discussion:
 - 2) Opportunity to elaborate on charge and suggest alternate means of increasing donor organs
- F. 11:20 Full group deliberation; Final Decision and Recommendation on question of Required Request
- H. 12:00 Lunch

Day 4; Friday, November 21 - Afternoon

- A. 1:15 Review of Charge to Panel: Individual-Oriented Programs/Population-Oriented Programs
- B. 1:30 Small group discussion:
 - 1) Response to a specific charge
- C. 2:15 Full group decision on specific charge.
- D. 2:45 Break
- E. 3:05 Small group discussion:
 - 2) Opportunity to elaborate on charge and suggest alternate means of creating an appropriate balance between programs
- F. 3:50 Full group deliberation; Final Decision and Recommendation on question of Individual-Oriented Programs/Population-Oriented Programs

Day 5; Saturday, November 22 - Morning

- A. 8:30 Full group review of Day 4 decisions
- B. 9:00 Review of Charge to Panel: Selected topics for consideration by the statewide Citizen's Panel on Transplants and Public Policy
- C. 9:30 Small group discussion
 - 1) Which health care question(s) should a statewide panel should consider?
- D. 10:15 Break
- E. 10:35 Full group decision on the above small group decisions
- F. 11:35 Small group discussion
 - 2) Regarding the questions under consideration in this panel, what do the panelists feel are the most appropriate ways in which these questions should be presented to a statewide panel?
- G. 12:00 Lunch

Day 5; Saturday, November 22 - Afternoon

- A. 1:00 Full group discussion of second small group decisions.
- B. 1:45 Break
- C. 2:00 FINAL REPORT on Conclusions and Recommendations to the Project Advisory Committee and Process Committee on:
 - 1) The issue of Required Request
 - 2) The question of resource balance between individually-oriented programs and population-oriented programs
 - 3) The recommendation as to which question(s) should be considered by a complete, State-wide Citizens Panel on Health Programs
- D. 3:00 Break
- E. 3:15 Evaluation
- F. 4:00 Closure