

*Health Care Law*

*Mid-Atlantic Ethics Committee Newsletter*

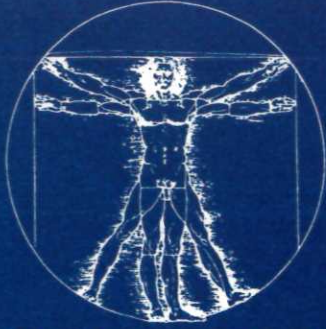
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Mid-Atlantic Ethics Committee  
Newsletter, Summer 1993

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# MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia  
Published by the Institutional Ethics Committee Resource Network  
Law & Health Care Program  
School of Law, University of Maryland at Baltimore

Summer 1993

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## USING CARDIAC DEAD PATIENTS FOR TRANSPLANTS: A NEW ISSUE FOR ETHICS COMMITTEES

According to Lori Brigham, Executive Director of the Washington Regional Transplant Consortium, nationally over 31,000 people are in need of an organ donation. Approximately 4,300 people consent to donate organs each year. The lack of organs available for transplant leads to approximately 2,300 deaths every year. Transplant professionals are hoping to increase the supply of organs available for donation by developing means of recovering organs from cardiac dead patients.

For the past 20 years organs have generally been recovered from patients who are brain-dead.<sup>1</sup> When a patient's brain has stopped functioning she is medically and legally dead, but her heart may continue to beat for several hours with artificial support. The artificial support supplies the organs with blood so that they continue to be healthy for a short time after brain death. This allows the patient's doctors time to seek out any advance directive regarding organ donation made by the patient, or approach the family and ask if they believe their

## Letter From the Editor

This issue truly represents a potpourri of subjects. Our cover story and case for discussion, by coincidence, both deal with the timely topic of the use of cardiac dead patients for organ transplants. This appears to be a new issue that some committees in Maryland, D.C. and Virginia are grappling with both in the area of policy development and case consultation. The issue also includes a piece by Dr. Henry Silverman, entitled "A Moral Constraint on Patient Autonomy" in which he outlines some of the current arguments in the bioethics literature for limiting the principle of patient autonomy as it applies to health care decisions. For the first time we have also included what some might call a human interest story, in which Dr. Ian Shenk describes some of the ethical dilemmas he confronted as a volunteer medical relief worker treating Somali refugees in Kenya. Finally, the issue includes the results of a survey of joint nursing home ethics committees in Maryland and how they are working. Please let us know if you have ideas for other topics you would like to see covered. Again, we hope you enjoy the issue.

Diane E. Hoffmann, Editor



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**Diane E. Hoffmann, J.D., M.S.,** Editor  
**Ruth Gaare, J.D.,** Co-Editor  
**Nancy Zibron,** Layout Editor

Contributing Editors:

**Louis Breschi, M.D.,** Chair, Professional Ethics  
Committee, Maryland Medical  
and Chirurgical Association  
**John Fletcher, Ph.D.,** Director, Center for  
Biomedical Ethics, University of Virginia  
**Sigred Fry-Revere, J.D., Ph.D.,**  
Independent Bioethics Consultant  
**Jackie Glover, Ph.D.,** Bioethicist,  
George Washington University Medical Center  
and Children's National Medical Center  
**Edmund G. Howe, M.D., J.D.,** Director of  
Programs in Medical Ethics, Uniformed Services  
University of the Health Sciences  
**Sanford Leikin, M.D.,** Director, Office of Ethics,  
Children's National Medical Center  
**Joan Lewis,** Coordinator, Washington Metropolitan  
Bioethics Network, D.C. Hospital Association  
**Steven Lipson, M.D.,** Medical Director,  
Hebrew Home  
**Franklin Miller, Ph.D.,** Bioethicist, Member,  
NIH Clinical Center Bioethics Committee  
**Jack Schwartz, J.D.,** Chief Counsel,  
Division of Advice & Opinions,  
Maryland Office of the Attorney General  
**Ian Shenk, M.D.,** Member, Fairfax Hospital  
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tee, University of Maryland Medical System  
**Peter Terry, M.D.,** Member, Johns Hopkins  
Hospital and Francis Scott Key Medical Center  
Ethics Committees  
**Jan Vinicky, M.A.,** Bioethicist, Washington  
Hospital Center  
**Margot White, J.D.,** Assistant Professor, Law &  
Ethics, University of Virginia, Center for  
Health Sciences

**The Institutional Ethics  
Committee Resource Network  
Law & Health Care Program  
University of Maryland School of Law  
500 West Baltimore Street  
Baltimore, MD 21201  
410/706-7191 or 410/706-7239**

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University of Maryland  
at Baltimore



## NETWORK NEWS

### Baltimore Area Ethics Committee Network

The Network last met on June 3rd at University of Maryland School of Law. Dr. Sanford Leikin, Director of the Office of Ethics at Children's National Medical Center spoke generally about his experience in "Making Health Care Decisions for Infants and Children" at Children's and how the Office of Ethics functions and interacts with the institution's ethics committee. He said that the ethics committee was established in 1984 and includes about 20 people two of which are community representatives. One is a parent of a handicapped child and the other is a relative of a child who died in the intensive care unit at Children's. He also said that the committee draws on the expertise of a "philosopher in residence." Since its beginning in 1984, the committee has heard approximately 40 cases. He said that most of the cases are initiated by staff but he estimated that about 25% come from parents. In addition to working with the ethics committee, the Office on Ethics, publishes a quarterly newsletter for the Medical Center called "Ethicscope" and conducts regular rounds including case presentations with residents and grand rounds. Dr. Leikin also commented on a recent case involving an infant at University Hospital.

Also, at the meeting, attenders were given a list of suggested topics for future meetings. The list included Medical Futility; Ethics Committee Process; Mediation for Ethics Committees; Evaluating Ethics Committee Performance; Education Programs--What Works?; Cultural Differences affecting Treatment Decisions; Ethics Committees in Long Term Care--Special Issues; Using Humanities to Discuss Bioethics Issues; and the new Maryland Health Care Decisions Act. Attenders were asked to rank the topics in terms of their interest for future meetings. The "top" scorers were: (1) Education Programs -- What Works?; (2) Cultural Issues Affecting Treatment Decisions; and (3) (a three way tie) Medical Futility, Using Humanities to

Discuss Bioethics Issues, and the new Maryland Health Care Decisions Act. Based on these results, the next network meeting to be held on September 9th at 4:30 p.m. will be on the topic of Educating Committee Members -- What works?

### Washington Metropolitan Bioethics Network (WMBN)

Since the last issue of the newsletter the WMBN has met twice. In May, the Network met at the headquarters of the District of Columbia Hospital Association. The topic was Religious Conflicts over Terminal Care. Speakers included Robert Veatch, Ph.D., John Kelly and Reverend Karen Morrow. In June, the Network met at Walter Reed Army Medical Center. The topic for discussion was "Problems in Surrogacy." Four cases were presented and discussed by a panel including an intensivist, a chaplain, a nurse researcher, and an attorney. The July meeting of the Network was cancelled due to scheduling problems. The Network is scheduled to meet again on September 21st from 4:00 - 6:00 p.m. at Mount Vernon Hospital in Alexandria, VA. The topic for the meeting is "CDE (Certified Death Educator) in the ICU: Reflections at the Gate." Mount Vernon Chaplain Joyce McCullough will discuss the role that a Certified Death Educator can play in the Intensive Care Unit and a decision-making model for ethical patient management in the ICU.

*Cont. on page 4*

### CORRECTION

In the last issue of the newsletter (Spring 1993) we neglected to give credit to Joan Planell, Administrator, Child Welfare Services, Montgomery County Dept. of Social Services, for the story entitled "A New Concept: Government Ethics Committees" (pp. 5 -6). Joan jointly submitted the article with John J. Kenney.



## Using Cardiac Dead Patients for Transplants

Cont. from page 1

relative would be interested in donating organs. If consent is obtained, the patient's heart, liver, pancreas, lungs and/or kidneys may be used for transplantation. Patients who meet the brain death criteria have generally suffered a traumatic head injury as a result of a motor vehicle accident or a shooting.

There are other patients who would like to donate organs after their death but are currently unable to do so, because although they are dead and meet the criteria for cardiac death, they do not meet the criteria for brain death. (An example of such a patient is described in the case on page 7.)

A number of hospitals are currently developing protocols for accepting organs for transplant from cardiac dead patients. In general, under the protocols, the organ is recovered after the patient's heart has stopped beating and they are declared dead. Since the heart has stopped beating it would not be available for donation. However, the kidneys are generally still healthy and some believe that the liver may also be able to be transplanted. The protocols allow for donation from patients who have been taken off a respirator as well as patients who have terminal brain damage but do not meet the standard for brain death. It would also include persons who died as a result of a heart attack.

The University of Pittsburgh has already developed a protocol for the recovery of organs from cardiac dead patients and two Washington, D.C. hospitals are attempting to do the same. A protocol put forth by Dr. Timothy Shaver at Walter Reed Army Medical Center is under consideration by the Washington Regional Transplant Consortium. The Consortium is one of sixty-eight federally designated organ procurement agencies in the nation that recovers organs for transplantation within a certain region. The Consortium keeps the local list of those patients who currently need transplants and are awaiting organs. They also

provide tissue recovery services (bone, skin and heart valves) and assist hospitals in procedures and protocol development for organ donation. The Consortium works with all of the hospitals in Washington, D.C. for organ donation and with its seven member hospitals (Children's National Medical Center, Walter Reed Army Medical Center, Washington Hospital Center, Fairfax, George Washington University Medical Center, Georgetown and Howard University Hospitals) which actively perform transplants.

Dr. Timothy Shaver, who is the head of transplantation at Walter Reed, has given the protocol to the Walter Reed ethics committee for review. The committee will analyze both the ethical and practical issues involved in implementing such a protocol. Dr. Shaver decided to bring the protocol to the committee for review because he has found it to be a good means of gaining hospital support. After the ethics committee has reviewed the protocol, Dr. Shaver plans to bring it to the hospital executives for approval. He hopes to have a finished product by September at which point he plans to use members of the ethics committee to educate hospital staff about this new procedure. Dr. Jimmy Light is currently developing a similar protocol for Washington Hospital Center.

Procuring transplants from cardiac dead patients raises both ethical and practical problems. It is accepted that in order to obtain organs the patient must be determined to be dead. According to the Uniform Determination of Death Act "an individual who has sustained either (1) the irreversible cessation of circulatory and respiratory functions, or (2) the irreversible cessation of all functions of the entire brain, including the brain stem, is dead."<sup>2</sup> Many ethicists are concerned that removing organs from cardiac dead patients results in a new definition of death. Some argue that such a patient could be revived in some circumstances, and the patient is then not irreversibly dead as required.

Physicians in favor of these transplants would respond that this argu-

ment is not effective because patients are routinely declared dead after only observing that their heartbeat and breathing have ceased to function. Also, they argue that there is no significant chance that the patient could be resuscitated when the physicians procure the organs. The issues of what type of care an organ donor receives, and whether it is proper to allow someone to die sooner to take organs to save another, even with their consent, are present with this method of organ procurement.

Another method for maintaining the organs is injecting the body with a preservation solution. This procedure was recently used in Illinois. The Regional Organ Bank of Illinois found that in deaths that occurred suddenly, families were unlikely to provide consent.<sup>3</sup> "After being refused permission in 35 consecutive cases," the Organ Bank decided to infuse preservation fluid to protect the organs so that doctors could provide the family with a few hours to deal with the patient's death before approaching them with the prospect of organ donation.<sup>4</sup> While the numbers of families who decided to donate organs increased while this procedure was used, the method is considered unacceptable to many commentators. They note that the fluid is injected into the dead patient's body with no consent from the family.

Other ethicists have raised concerns about the costs associated with the procedure. They look at the high expense involved in transplantation and believe that these resources would be best utilized in other areas of health care such as providing care for the poor. This dilemma runs throughout the health care field.

The practical considerations of implementing such a policy are also difficult. Cultural and religious beliefs may make some staff uncomfortable with removing organs from cardiac dead patients. Education may be an important factor in allowing staff to accept and implement this new means of procuring organs for transplant.

Transplantation continues to be a controversial area of medicine. This

*Cont. on page 4*

## Using Cardiac Dead Patients for Transplants

Cont. from page 3

new procedure provides an opportunity to provide more transplants for the long list of those in need. However, the protocols developed by the hospitals should address the problems both the staff and the public may have with this new procedure.

Submitted by  
Jennifer Levin  
JD Candidate  
University of Maryland  
School of Law

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1. Colburn, D. *Changing the Life-And-Death Rules for Transplants*, *Washington Post*, 6/15/93.

2. Youngner, S.J. *Ethical, Psychosocial, and Public Policy Implications of Procuring Organs From Non-Heart-Beating Cadaver Donors*, *JAMA*, June 2, 1993-Vol 269, No. 21.pg. 2772.

3. *Id.* at 2770.

4. *Id.*

## Network News WMBN

Cont. from page 2

The Network's October meeting has been scheduled for Tuesday October 19th from 4:00 - 6:00 p.m. at The Washington Home in the District. The program will focus on such questions as what decisions can mentally impaired adults make in both hospital and nursing home settings. The November meeting is scheduled for November 16th from 4:00 - 6:00 p.m. at the Hospital for Sick Children, also in the District. A topic has not yet been announced. For more information on the Network or any of these meetings call Joan Lewis, Network Coordinator, at (202)682-1581.

## West Virginia Network of Hospital Ethics Committees

In May, the Network sponsored their 6th annual education symposium. It

was attended by 147 participants from over 60 health care organizations. It featured a debate between William Batt, Ph.D., a national board member of the Hemlock Society and Burke Balch, J.D., legislative director for the National Right to Life Society. Also, this summer the Network sponsored a 2-1/2 day intensive course in bioethics for 64 people from 24 institutions. On September 24th, the Network is sponsoring a forum on "Institutional Compliance with JCAHO Patient Rights Standards." The forum will be held in Flatwoods, West Virginia and the speaker will be Ann Kobs, R.N., M.S.N., Associate Director for Standards of JCAHO. For further information about the event, call (304)293-7618.

## The Bioethics Resource Group, Charlotte, NC

The Bioethics Resource Group, a community based educational organization, will sponsor a forum on September 13, 1993 at 7:30 p.m. with Dr. John Stone on Physician-Patient Communication.

Although the Group does assist hospitals in establishing ethics committees, its major focus is public education. By working with the press and providing speakers to civic clubs and church groups, director Katherine B. Thompson says the Bioethics Resource Group is working to heighten awareness that health care issues are not just the concern of the health care professions but the responsibility of society at large. With strong support from the local medical society and hospitals in the area, as well as from a corporate grant, the Group is now working to establish a network outside the Charlotte metropolitan area.

For further information, contact Katherine Thompson, (704)332-4421.

## A MORAL CONSTRAINT ON PATIENT AUTONOMY

The principle of autonomy has been a cornerstone in medical ethics during the last thirty years, but recently, there has been a concern expressed with an absolute deference to patients' interests in the sphere of end-of-life medical treatment decision-making. It appears that, although the recognition of autonomy in the medical arena has helped diminish the practice of paternalism, the swing towards autonomy may need a corrective force.

The problem, as stated by David C. Thomsma, Ph.D. at a recent conference sponsored by the International Bioethics Institute this April, is that autonomy "glorifies the individual in society to the detriment of the community." Indeed, a major flaw with the current thinking is that medical treatment decisions affect only the life of the patient or that its impact on other lives should be ignored. Instead, John Hardwig argues that many treatment decisions inevitably and dramatically affect the quality of more lives than one, and therefore, the interests of others need to be considered in the decision-making process. Hence, the principle of distributive justice, which supports the consideration of families' and as well as society's interests, competes with the principle of autonomy.

This new approach to decision-making takes into account the essential interplay between rights and responsibilities. In addition to having rights, members of society must also recognize the responsibilities and obligations that one has towards the other members of the social unit, whether it be the family or society. This concept has at its foundation a notion of "human connectiveness" and arises out of perceptions of human beings as relational, interdependent, and supportive.

To incorporate this new approach to decision-making, one needs to clarify and assign relative weights to the family and societal interests that could legitimately constrain patient-centered



decisions. For example, when does it become ethically defensible to withhold or withdraw medical interventions from patients based on the financial burdens that families or society may incur from that treatment? When do emotional concerns of families become morally relevant? How does one distinguish between morally repugnant conflicts of interest and morally relevant conflicts of interest?

The notion that some family and societal interests may be morally legitimate in medical decision-making has profound implications for the concept of ethics committees as being the patient advocate. Indeed, in the State of Maryland, the concept that ethics committees are to serve patients' interests is emphasized by the legal name given to these committees: Patient Care Advisory Committees. A broader perspective for ethics committees, however, may be necessary. To familiarize oneself with the arguments for the justification of placing limits on patients' interests, references to articles in the recent literature on this subject are given below.

1. Hardwig J. *What about the family?* *Hastings Center Report*. 1990;20:5-10.
2. Hardwig J. *The problem of proxies with interests of their own: Toward a better theory of proxy decisions.* *The Journal of Clinical Ethics*. 1993;4:20-27.
3. Jecker NS. *Being a burden on others.* *The Journal of Clinical Ethics*. 1993;4:16-20.
4. Strong C. *Patients should not always come first in treatment decisions.* *The Journal of Clinical Ethics*. 1993;4:63-66.
5. Carse AL. *Justice within intimate spheres.* *The Journal of Clinical Ethics*. 1993;4:68-71.
6. Nelson JL. *Taking families seriously.* *Hastings Center Report*. 1992;22:6-12.
7. Blustein J. *The family in medical decisionmaking.* *Hastings Center Report*. 1993;23:6-13.
8. Emanuel EJ. *A communal vision of care for incompetent patients.* *Hastings Center Report*. 1987;17:15-20.
9. Brock DW. *What is the moral basis of the authority of family members to act as surrogates for incompetent patients: The Journal of Clinical Ethics*. 1992;3:121-123.

Submitted by  
Henry Silverman, M.D.

## ETHICAL PROBLEMS IN PROVIDING MEDICAL CARE TO SOMALIAN REFUGEES: AN ETHICS COMMITTEE MEMBER'S EXPERIENCE

During February and March 1993, I visited Wajir, Kenya on the southwestern border of Somalia and provided medical care in surrounding refugee camps and villages to the Somali refugees who had fled from their native country to escape the devastation in their homeland. These are nomadic peoples who have no indigenous medical care except for faith healers who prescribe limited herbal medicines or apply heated metal or wooden sticks to areas of discomfort believing that these burns alleviate the underlying disease. While my principal intellectual and emotional responses to this situation were those of sorrow and frustration, I was occasionally aware of the "ethical" dimensions of the situation. Perhaps in my naivete I had never realized the very simple fact that the host country rarely appreciates the presence of refugees on their soil. This proved to be the case when it became readily apparent that the Kenyan government did little to support (except with great reluctance) the relief effort in this region. The government not only regulated our refugee-directed activities but also forbade our delivery of any health care services to the Kenyan residents of the area. This was most unfortunate because the Kenyan health system was woefully inadequate, and the general level of health care available to the native Kenyans was very little better than that available to the Somali refugees.

Our supply of medications was never adequate, and our re-supply though warehouses in Nairobi was often delayed and always insufficient. On one occasion when we were in the midst of a malaria epidemic and our supplies of anti-malarial medication were depleted, the Kenyan government and the UNICEF facility in that district refused to provide us with the necessary medication which was available in local warehouses. This refusal was

entirely politically motivated.

The local health system was horribly inadequate, little medication was available even at the district hospital, and patients were required to pay for their medication. If they had no money, they received no medication. There were no blood banks, and patients requiring transfusion would either have to arrange for a family member to donate or have to pay a stranger or unrelated villager an often exorbitant sum of money. The blood was not screened for communicable diseases, nor was it typed and cross-matched!!! Our medical team was occasionally approached to provide money for such a necessary transfusion (oftentimes in circumstances when certain death was the consequence of the patient not being transfused). To respond to such a request for financial support in one instance would most assuredly invite literally hundreds if not thousands of similar requests within a short period of time. What does one do when these funds are necessary to purchase medications to carry on the relief effort? Similar requests were made for monies to purchase shrouds to bury the countless dead who died penniless.

And finally, when medications did become scarce, we were faced with the question of whether to withhold medication from individuals with minor illnesses knowing full well that someone with a more serious illness treatable with the same medication would soon appear??? Such were the ethical dilemmas with which we dealt on the southwestern border of Somalia during February and March of 1993.

Submitted by  
Ian Shenk, M.D.  
Member, Fairfax Hospital and  
Reston Hospital Center  
Ethics Committees



# NURSING HOME ETHICS COMMITTEES: SURVEY OF JOINT COMMITTEES

The Maryland Patient Care Advisory Committee Act requires all hospitals and nursing homes within the state to establish a patient care advisory committee or ethics committee. Nursing homes can fulfill that requirement by (1) establishing their own ethics committee; (2) joining with a hospital to establish a committee; or (3) joining with a number of other nursing homes (up to 30) to form a committee. There are a number of reasons for establishing a joint committee. Arguably, requiring each health care facility to establish their own committee is a waste of resources, and the goal of access could be more efficiently achieved by having community committees or joint committees that would serve more than one institution. Theoretically, with fewer committees, more resources could be spent on educating members. Case consultation might also improve under a joint committee system, and committees would be less likely to be criticized for representing the interests of the institution rather than those of the patient.

There are several models for establishing joint ethics committees. A geographic model (committees in the same geographic region come together) has the advantage of proximity, but some disadvantages, as well. Problems can arise if the homes do not share the same culture or values, or if the facilities are competitors and unwilling to share information, or if they simply have a different way of doing things. Other models include large nursing home chains that have a corporate structure that allows them to centralize activities such as ethics committees and a model that is based on shared philosophy or values. This last model could include a group of facilities run by the same religious denomination, i.e. a group of Catholic nursing homes.

Last year the Health Facilities Association of Maryland (HFAM) held

a series of workshops for groups of nursing homes around the state to assist them establish joint ethics committees based on the geographic model. At the workshops, HFAM asked those in attendance to indicate to HFAM if they were interested in participating in a joint committee. Based on the responses, HFAM organized the facilities into eight joint committees or clusters--three in the Baltimore area, two in Montgomery County, two in western Maryland and one on the eastern shore. Each cluster consisted of four to six facilities. This past spring, Lynn Carr, Assistant Administrator, Bethesda Rehabilitation and Nursing Center, and Diane Hoffmann of the University of Maryland School of Law informally surveyed these nursing homes to find out whether the joint committees were working, or if they were not, why not?

## Survey Responses

Since their inception, six of the original eight clusters remain. Some have regrouped, expanded or contracted and each varies in its approach to organization and operation.

Those nursing homes that continue to participate in a cluster cited assurance and validation when making complex decisions as an advantage of participating in a joint committee. They found that sharing the responsibility of decision-making with other administrators and professionals increased the comfort level during this process. Respondents also stated that participation in joint committees led to forming and/or expanding working relationships with peers and resulted in much needed support in a highly competitive business.

Joint committee meetings also served as a source of in-depth information on law and bioethics. There was more heterogeneity and a wider range of values and questions raised during these meetings than in meetings of a single nursing home. There was also a keener awareness of the issues and permission to explore more options and ideas. Outgrowths of the joint committees included updating of facility policies and procedures,

more inservices and dealing differently with residents and families. Respondents also found that in a joint committee there was a greater likelihood of being able to avert going to court when unable to resolve disputes.

Joint committees also seem to encourage objectivity among their members--members could more easily detach themselves from the emotional turmoil of a case, seek out options available and bypass conflicts of interest. One respondent said there was more of a sense of a "fair hearing" during a case consultation in the petitioner's eyes when they were able to speak to a doctor and administrator outside of their own facility.

Facilities with limited resources, such as only one physician, especially found the joint committee system to be an advantage. Some members had their own internal committee but also participated in a joint committee. In those cases, members stated that they found the joint committee to provide "extra insurance," meaning that they could fall back on the joint committee structure when needed.

Joint committees were also found to be a source of professional growth, intellectual stimulation and gave members a "moral boost."

Some members, however, found it a disadvantage to have to travel outside of the building for meetings and disliked the short amount of notice sometimes given for a case consultation meeting. They also found it difficult for the Chair to locate representatives who were available to attend meetings, and other members stated that there were more pressing priorities competing for their limited time.

Some committee members said that cases were not being referred to them and that no one was aware of their existence or understood their role. Consequently, they had not functioned as a committee as yet. Other committees were not firmly established and their members were frustrated at the amount of time spent formulating procedures, finding a leader and reaching a stage where they were able to review cases. One respondent



indicated that there was a conflict between the values and culture of the joint committee and an individual facility.

Other disadvantages cited included the difficulty of getting M.D.s and pastors to participate, the poor communication within their joint committee and between their committee and others, and a lack of change in the committees' status quo. As regards the last factor, one respondent stated that unilateral decisions were still being made in their facility by the Director of Nursing, the administrator and/or physician.

### Vital Committees

There are several traits shared by joint committees that appear to be functioning effectively. These "vital" committees have access to necessary resources and adequate leadership. "Vital" committees were more willing to share information and air internal problems, although this trait was more likely to be evident when facilities shared the same corporate parent. Effective joint committees also had an administrative structure in place before formation of the committee. "Vital" committees were put to innovative uses—The Meridian Nursing Home takes a more active public policy role and uses its committees to review any proposals for research on its residents. Finally, "vital" committees are more likely to utilize outreach. An example is the committee that sent a memo to its residents and their families explaining the role of the ethics committee and how to access it.

There are also a number of traits that are shared by committees that are not functioning effectively. As one might guess, these committees do not have adequate leadership, are unwilling to devote resources to improving the committee, seem to lack expertise, are unwilling to air their internal problems, exhibit an incompatibility within and between committees and members, and in some cases, appear to be too controlled by their legal counsel.

## Case Presentation

*One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee in the region and how the committee resolved it. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.*

## Case Consultation in a Virginia Hospital

### PRESENTATION: THE CASE OF MR. J.

Mr. J. was diagnosed nine years ago, at the age of 46, with amyotrophic lateral sclerosis (ALS), a fatal degenerative neurological disease characterized by progressive muscular weakness. By the age of 50, Mr. J.'s disease had progressed to the point that he was dependent on a mechanical ventilator for his breathing.

Four years ago, Mr. J. decided that his quality of life was such that he wanted the ventilator withdrawn, knowing that death would soon follow. He communicated this wish to his physician, Dr. A., a neurologist in private practice, who had been following Mr. J. since the onset of his ALS. Dr. A. did not feel that he could personally carry out Mr. J.'s request for removal of the ventilator. He understood and was sympathetic to Mr. J.'s plight, and contacted a colleague, Dr. B., at a large medical center in another city who might be willing to accept Mr.

J. as a patient and to honor his wish for withdrawal of life-sustaining treatment. After a thorough evaluation of Mr. J.'s case, Dr. B. decided that he would be willing to accept Mr. J. as a patient and that he could honor Mr. J.'s request to have life-sustaining treatment withdrawn. Prior to effecting the transfer, Dr. B. asked the Ethics Consultation Service to review the ethical issues in the case. The consultation service saw no ethical obstacles to treatment withdrawal. Once given the option to have the ventilator withdrawn, Mr. J. elected to defer withdrawal until some time in the future.

Four months ago, Mr. J. contacted Dr. B. and reiterated his wish to have the ventilator withdrawn at some future time. He also communicated a desire to donate his organs upon his death. Uncertain of the ethical issues involved in meeting the request, Dr. B. again contacted the Ethics Consultation Service and requested assistance in resolving the case. There was general consensus that Mr. J.'s wish to donate his organs posed no inherent ethical issue, and was as legitimate as any other individual's request for organ donation. The procedural issue of how the organs would be harvested following treatment removal did pose some questions that the ethics consultants felt should be explored so that Mr. J. could be informed. Contact was made with the medical center's organ procurement office.

It was discovered that no current organ harvesting protocol existed at the institution that would allow for Mr. J.'s wish to be met. The organ procurement coordinator stated that he had about ten such requests per year for organ donation following removal of life-sustaining treatment. He asked permission to submit a protocol for consideration by the Ethics Committee that had been adapted from one developed at the University of Rochester involving organ harvesting from donors following the withdrawal of life support. Such patients would be declared dead two minutes after their hearts stopped beating, but before they could be declared brain dead. Their organs would be lavaged with cooled saline solution via a peritoneal catheter. After the family had spent time with

*Cont. on page 8*



## Case Presentation

Cont. from page 7

the deceased patient, he or she would be transported to the operating room for organ harvesting.

In order to meet Mr. J.'s request for organ donation following the withdrawal of life support, the Ethics Committee would have to approve the new protocol for organ harvesting from non-heart-beating donors. Should the protocol be approved?

Submitted by  
Mary Faith Marshall, Ph.D.  
Center for Biomedical Ethics  
University of Virginia  
Charlottesville, VA 22908

## Case Discussion: A Bioethicist/Lawyer's Perspective

Few ethical issues are as perplexing as those involving organ donation. The case of Mr. J. is confounded by many potential ethical and legal misunderstandings. My goal in this comment is to help the reader distinguish what issues are at stake in the case of Mr. J.

### Does Mr. J. Need To Be Brain Dead Before His Organs Can Be Harvested?

From a legal standpoint Mr. J. does not need to be brain dead before his organs are harvested. We have become so accustomed to speaking of death in terms of brain death that we have forgotten that in all fifty states, death may be determined either by respiratory/circulatory or neurologic criteria. If a patient's respiratory/circulatory functions have stopped the patient need not also meet neurologic criteria to be considered dead.

From a philosophical perspective we may wish to reevaluate the legal definition of death. Have neurologic criteria become so central to our notion of personhood that mere respiratory/circulatory criteria are no longer acceptable?

### Must the Cessation of Mr. J.'s Respiratory/Circulatory Functions be Irreversible Before He Can Be Considered Dead?

It is difficult to think of Mr. J. as being dead immediately after disconnecting him

from the ventilator which makes his respiratory and circulatory functions stop because in all likelihood it would be possible to restore those functions even once they have stopped. Death is commonly understood as being permanent and the law has maintained that requirement. Yet, in states like Virginia, the requirement that death be irreversible is achieved when the patient's physician determines that "attempts at resuscitation would not . . . be successful in restoring spontaneous life-sustaining functions . . ." Mr. J. would be legally dead as soon as he stopped breathing and his heart stopped since due to his ALS it was clear he could never again breathe spontaneously.

The suggested protocol creates some confusion by adding the requirement that there be a two minute waiting period after the heart stops before declaring a patient dead. It is most likely that this requirement is intended to account for the possibility of auto-resuscitation. The addition of such a requirement, independent of whether it is sufficient from a medical standpoint,<sup>2</sup> is not required under Virginia law. Quite the contrary, Virginia law specifically leaves the physician an option of either basing his or her pronouncement on a passage of time since respiratory/circulatory functions ceased or on a conclusion that the underlying disease or condition has directly or indirectly caused the patient's respiratory/circulatory functions to cease.

The legal solution of considering a patient dead even though it still may be possible to maintain that patient's respiratory/circulatory functions artificially may make some people uneasy. Why is a person considered alive while he or she is ventilator dependent but not considered alive if, once respiratory/circulatory functions have ceased, a ventilator dependent life is the only life to which he or she could be restored? Note that this problem does not exist when neurologic criteria are employed. A brain dead ventilator dependent patient is dead.<sup>3</sup>

### Should the Protocol Be Approved?

From a legal perspective there is no reason why the suggested protocol could not be implemented at a Virginia

hospital. Furthermore, it would be acceptable to eliminate the two minute waiting period and pronounce death as soon as respiratory/circulatory functions have ceased and the patient's physician believes that spontaneous life-sustaining functions can no longer be restored.<sup>4</sup>

From an ethical perspective it would be important for members of the ethics committee to carefully consider their own ethical concerns before either approving or disapproving a protocol under which organs could be harvested from non-heart-beating patients like Mr. J. First, the ethical concerns regarding the definition of death already mentioned above need to be resolved. Second, the committee may wish to consider other related ethical issues such as: 1) From a utilitarian perspective, is our need for organs so great that it would be just to allow dying patients to consent to having their organs harvested even if there is some uncertainty as to whether or not these patients should be considered dead? 2) From a deontological perspective, is autonomy of such an overriding importance that dying patients have a right to request that their organs be harvested while still viable even if doing so may mean taking them before death is certain? 3) How can conflicts of interest between a physician's duty to the dying patient and a desire to provide organs to save another patient's life be resolved? Under Virginia law the physician who declares death may not participate in the procedure for removing or transplanting an organ.<sup>5</sup> Is this enough of a precaution or should there be other precautions as well?

For an in depth discussion of these issues and others related to organ procurement from non-heart-beating patients reference the latest issue of the *Kennedy Institute of Ethics Journal* Vol. 3, No. 2 which is totally devoted to a discussion of this topic.

Submitted by  
Sigrid Fry-Revere, J.D., Ph.D.  
Independent Bioethics Consultant

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1. Va. Code Ann. §54-1-2972 (1993)  
Emphasis added.

2. Lynn, Joanne "Are the Patients Who Become Organ Donors under the Pittsburgh Protocol for 'Non-Heart-Beating Donors' "



*Really Dead?*'' Kennedy Institute of Ethics Journal 3(2) (June 1993). p. 167.

3. See Va. Code Ann. §54-1-2972 (1993).

4. *Id.*

5. *Id.* at § 32.1-295 (1993).

## Case Discussion: Comments From A Neurologist

The protocol submitted to the Ethics Committee by the Organ-Procurement Coordinator in this case is the essence of brevity. In very broad terms it may satisfy minimal criteria to allow this one single patient to achieve his two goals of discontinuing therapy and to be a non-heart-beating organ donor. It would appear inadequate however as a general policy for a large medical center because several areas are undefined and/or vaguely addressed potentially leading to confusion or conflicts. Needs of the patient, the surviving family, the organ-procurement team, society and the organs themselves each have a role in this deliberation.

Organ donation from non-heart-beating donors at Univ. of Pittsburgh was recently critically reviewed in an excellent monograph (Kennedy Inst. of Ethics Journal Vol. 3, Number 2, 1993) which probed a number of controversial areas.

In Virginia the traditional diagnosis of death requires cessation of respiratory and cardiac function, the latter reasonably defined as the ability to generate a measurable blood pressure. But, how long should one wait to determine if function is lost? At one extreme, waiting only seconds would allow a conclusion of "lost function" between normal heart beats while at the other, waiting 30 minutes to document lost function jeopardizes organ viability. In their effort to shrink the delay in diagnosing death, Pittsburgh proposed several cardiac electrical criteria which have not yet been critically tested. Mr. J. would be observed for two minutes after loss of heart beat which seems an arbitrary delay and suggests a sense of uncertainty about the procedure. Once the heart beat (blood pressure) has been recognized to have stopped, which is already a defined parameter in the given

protocol, further delay is superfluous. Is there a blood pressure or is there not?

Another concern is raised by including, "... but before they could be considered brain dead." The diagnosis of death requires either cardiorespiratory or cerebral criteria but not both. Have we now the situation where invasive, painful procedures are to be performed as soon as possible on potentially "brain alive" patients? Is it therefore appropriate to administer analgesic/anesthetic agents to perform surgery for organ donation, apart from any such agents provided for comfort measures upon cessation of life-supporting treatment? Also although circulation has stopped, iced peritoneal lavage could theoretically lower brain metabolism and actually protect some cerebral activity, as witnessed by the therapeutic intervention of hypothermia.

For Mr. J., donation of his vital unpaired organs will actually enrich his life, a seemingly paradoxical situation. Unlike other cases where surrogates are deciding, Mr. J. personally requested the donation. Therefore, he must be dead (enough) to donate but not (so) dead that donation is thwarted. For those who demand an irreversibility test for failure of cardiorespiratory function we must remember that Mr. J. requested termination of life support. He does not want attempts to reverse organ failure so tests of reversibility are unjustified and could derail both of his goals.

No data are provided about any family of Mr. J. Family are allowed to "... spend time with the deceased...." before organ removal but the actual length of time is critical to the entire procedure. For the family of Mr. J. or any other cases this vital aspect needs to be addressed squarely, in advance, with sensitivity and respect.

The attempt to define the transition from alive to dead mirrors a similar frustration in differentiating normal from altered consciousness neurologically. All can recognize a convulsive seizure as a loss of consciousness but a departure from normal consciousness can also be shown electrophysiologically as a delay in response-time in a patient who appears fully normal clinically during the first few seconds of

a generalized seizure discharge in petit mal epilepsy. Thus definitions can be revised as more advanced technology is applied and as there is a need to do so.

Finally, Mr. J.'s neurological disease is often stated to be one that should never come to ventilatory support because of its inexorable and rapid progression to death and because it is said to be easier not to start a treatment than it is to discontinue it. Mr. J., however, is now over 9 years since diagnosis and over 5 since tracheostomy. ALS is, indeed, currently an incurable illness which is not, however, equivalent to a terminal illness. Patients can be successfully sustained at a variable level of function with standard, albeit, invasive treatments for an indeterminate duration until someone decides (as did Mr. J.) that the benefit of these treatments is insufficient, at which point the patient with ALS only then has a terminal illness. The disease we identify as ALS probably has several different causes of which we know virtually none, and certain patients can retain useful function with minimal intervention for considerable time, although it is hard to recognize them as a unique group prospectively.

Submitted by  
Ivan S. Login, M.D.  
Professor of Neurology  
University of Virginia  
Health Sciences Center

## MACK VS. MACK: COURT GRAPPLES WITH RIGHT TO DIE

*In the first issue of the Mid-Atlantic Ethics Committee Newsletter, we reported on the Maryland case of Mack v. Mack. Since that report, the case has worked its way up to the Maryland Court of Appeals, Maryland's highest court and through the process of remand back to the trial court. Now that the case appears to have come to a close, we have included a summary of its journey and resolution from the perspective of Rachel Wohl, attorney for Deanna Mack.*

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## Mack vs. Mack

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Ronnie Mack is a relatively young man who has spent the past 10 years of his life in a persistent vegetative state. His body continues to function, but his cerebral hemispheres are so damaged that he has no awareness of himself or of others. He is emaciated and his limbs are bent and rigid. He spends his days and nights in a VA hospital bed. A neurologist and a neurosurgeon who have examined Ronnie have both concluded that there is no reasonable chance that he will ever improve. There is no documented case of anyone having recovered from a persistent vegetative state after more than 22 months.

The legal brouhaha began when Ronnie's wife, Deanna Mack, decided that it was time to disconnect Ronnie's feeding tube and allow him to die. She firmly believed that Ronnie would choose this course were he aware of his condition. But when Mrs. Mack began making efforts in this regard, Ronnie's father went to court and got a temporary injunction to stop her. Ronnie's father and sister strongly oppose any attempts to end Ronnie's life. Despite the medical findings, they are convinced that they communicate with Ronnie and they believe that a miracle could bring Ronnie back to consciousness.

A trial was held in Baltimore County Circuit Court to answer two basic questions. First, what did Ronnie Mack indicate, before his accident, that he would want to have happen in these circumstances? Second, who should be appointed as Ronnie's legal guardian?

Ronnie's wife and others presented evidence that Ronnie had made statements about his senile grandmother, and about a close friend who had been shot, which indicated that he would not want to live in a physically dependant condition. The evidence also showed that Ronnie hated doctors and hospitals, had refused medical care in the past--had even refused to take his sick infant son to a hospital emergency room. He placed a very high value on physical fitness. He was a consummate athlete and bodybuilder.

Ronnie's father and sister presented evidence that after Ronnie's mother died from a sudden aneurism when he was 10-years-old, he said that he

wished the doctors had operated on her, even though they said that she would be, at best, "an eighty percent vegetable." They concluded, therefore, that Ronnie would want to be kept alive, himself, as a 100% vegetable.

Following a three day trial, the court ruled that the evidence was inconclusive with regard to what Ronnie would want in this circumstance. The court stated that it had to be persuaded by "clear and convincing evidence" that prior to his accident, Ronnie had indicated that he would remove the feeding tube in this circumstance.

The court posed an impossible task. Ronnie Mack was a high school graduate from a working-class family in Essex. He had never heard of artificial nutrition and hydration, nor did he contemplate having his life sustained in a persistent vegetative state. It is very doubtful that Ronnie knew what a persistent vegetative state was. How could anyone possibly prove by clear and convincing evidence that Ronnie had determined, prior to his accident, that if he should fall into a persistent vegetative state, he would refuse artificial nutrition and hydration? Ronnie never had the basic knowledge or experience to make such a determination.

On the issue of guardianship, the court stated that it would grant guardianship to Deanna Mack if it decided to withdraw life support, and it would give guardianship to the father if it decided to refuse withdrawal. Counsel for Mrs. Mack argued that, because of her statutory priority, Mrs. Mack should be her husband's guardian whatever the court decided. The court, however, granted guardianship to the father based on its decision to deny withdrawal of life support.

Mrs. Mack appealed the court's decisions, to Maryland's "supreme court," the Maryland Court of Appeals. *Mack v. Mack*, 329 Md. 188, 618 A.2d 744 (1993). The high court agreed with the circuit court that the right to refuse life sustaining medical treatment is recognized in Maryland. It further agreed that this right is not lost when one becomes incompetent. In addition, it agreed that the right includes refusal of artificial nutrition and hydration. Finally, the court agreed that a petitioner must present "clear and convincing evidence" that the patient would choose to remove the feeding tube under the circumstances.

The Court of Appeals disagreed with the Circuit Court on only one issue. It

remanded the guardianship determination back to the Circuit Court, instructing the circuit court that petitioning to withdraw life support is not good cause to skip over a spouse's guardianship priority.

The Circuit Court had already determined that Mrs. Mack loved her husband, was sincere in her efforts, and did not stand to gain financially by her husband's death. She had acted as his guardian for seven years, without complaint by anyone. Nevertheless, on remand, the Circuit Court again appointed Ronnie's father as his guardian. The Court reasoned that because the wife lives out-of-state and only visits a few times each year, the father could better care for Ronnie's physical needs and found, by a clear and convincing evidence standard, that the father's proximity provided good cause to skip over Mrs. Mack's statutory priority.

In its attempt to resolve this disagreement, the judicial system illustrated its limitations in dealing with complex moral issues. In essence, the larger effect of the court's ruling is that all those who have not specifically stated or written their wishes, should these terrible circumstances arise, may be destined to be maintained in a persistent vegetative state--indefinitely. The old maxim that the court should always err on the side of life has had a perverse effect in this circumstance. Here, the court is bending over to favor the use of medical technology to maintain bodies in a state that many consider abhorrent.

Ronnie's doctors say that he could be maintained in his persistent vegetative state for the next forty years--at exorbitant cost to the VA and federal tax payers. His wife and two children, effectively, have no further recourse.

Unfortunately, the new Maryland Health Care Decision Act, passed in the last legislative session, will not affect this circumstance where close family members are in conflict. It appears that under the new law, if a family member brings such a dispute to the courts, the *Mack* scenario will be played out again--with the court demanding proof that most people are unable to provide. The only realistic protection from the limitations of the courts in this arena is the execution of advance directives. Yet, as we all know, although more and more people are executing advance directives, their use is far from universal--especially among the young.

Submitted by  
Rachel A. Wohl, Esquire  
Brown, Goldstein & Levy  
Attorneys for Deanna Mack



# CALENDAR OF EVENTS

## SEPTEMBER

- September 9th Baltimore Area Ethics Committee Network Meeting, 4:30 - 6:30 p.m. Topic: Educating Committee Members: What Works? Location--TBA. For more information call (410)706-3378.
- September 9th - 12th Seventh Annual Meeting of The Society for Bioethics Consultation, Cleveland Marriott Society Center, Cleveland, Ohio. Topic: Unity and Diversity in Bioethics Consultation. For more information, contact Society for Bioethics Consultation, Department of Bioethics, P-31, Cleveland Clinic Foundation, 9500 Euclid Avenue, Cleveland, OH 44195.
- September 14th Conference on "Implementing the Maryland Health Care Decisions Act: Questions and Answers," 8:30 - 4:00 p.m. Veterans Affairs Medical Center, 10 North Greene Street, Baltimore. Sponsored by the Law & Health Care Program of the University of Maryland School of Law and the Maryland Office of the Attorney General. For more information and/or a conference brochure call: (410)706-3378 or 7239.
- September 17th Shore Memorial Hospital Bioethics Committee's Fifth Annual Bioethics Conference, 8:30 - 5:00 p.m. The Flanders Hotel, Ocean City, NJ Topic: Rationing Health Care . . . American Style. Featured Speakers: George Annas, JD, MPH; Paul Armstrong, JD (attorney in the case of Karen Quinlan); Chris Cruzan White (Executive Director Nancy Cruzan Foundation); Richard Pothier (Journalist and Heart Transplant Recipient). For more information contact: Sally Nunn, Shore Memorial Hospital Bioethics Committee, Somers Point, NJ.
- September 21st Metropolitan Washington Bioethics Network, 4:00 - 6:00 p.m. Mount Vernon Hospital, 2501 Parkers Lane, Alexandria, VA. Topic: "CDE (Certified Death Educator) in the ICU: Reflections at the Gate."
- September 24th West Virginia Network of Hospital Ethics Committees, Forum on "Institutional Compliance with JCAHO Patient Rights Standards." Flatwood, West VA. For more information call (304)293-7618.

## OCTOBER

- October 5th First Class. Course on Health Care Ethics: Issues and Applications, 6:15 - 9:15 p.m. Loyola College Columbia Business Center. Columbia, MD. Offered by The Sellinger School, Loyola College in Maryland. For more information call (410)617-5061.
- October 19th Metropolitan Washington Bioethics Network Meeting, 4:00 - 6:00 p.m. The Washington Home, 3720 Upton Street, NW, Washington, D.C. Topic: Decision-making for mentally impaired adults.
- October 22-23 American Society of Law, Medicine & Ethics' 1993 Annual Meeting. The Doubletree Hotel, Arlington, VA. Topic: Health Care Priorities, Policies, and Practices in a New America: Legal and Ethical Insights. For more information call: (617)262-4990.



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