NETWORK NEWS

The newsletter of the Florida Bioethics Network

a Health Service Group of the Florida Hospital Association - P.O. Box 531107 - Orlando, Florida 32853-1107 - 407-841-6230

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PRESIDENT'S MESSAGE

Submitted by Hana Osman, LCSW, DCSW, Manager/Social Work Department, Tampa General Hospital, Tampa.

The fifth annual conference of the FBN is now behind us. One hundred and eight registrants participated in the conference and the valuable comments we collected will guide the planning of the 1996 seminar. This input also will help shape the goals of FBN for the next year. You have indicated that the following areas are of interest:

- Organizational ethics
- Business ethics and conflict of interest
- Ethics and managed care
- Patient advocacy
- ▶ Ethics committees and clinical consultation

The requirements and recommendations of the Joint Commission drive the continuing interest in business and organizational ethics. Clinical interest will remain the driving force behind the concerns about ethics and managed care, patient advocacy, and the development and maintenance of ethics committees and their clinical consultation function.

As the FBN 1996 goals evolve, and as the areas of concern crystallize, the *Network* News will be used to communicate with our members. On behalf of your Board, I extend an invitation to you to contribute to the *Network News* and to participate in shaping the goals for your Network.

THE MIRACLE OF TRANSPLANTATION AND THE SCARCITY OF ORGANS: CAN WE ETHICALLY SOLVE THE PROBLEM?

Submitted by **Glenn Singer, MD, FACP, FCCP,** Chairman-Bioethics Comm./Pulmonologist, Broward General Medical Center, Ft. Lauderdale.

In 1994 the United Network for Organ Sharing (UNOS) reported over 40,000 people waiting for organs, yet only 18,251 transplants were done. High profile recipients such as actors, athletes, and politicians often raise questions about allocation of organs and how scarce resources are used in the community. The short supply is a result of several factors. Improved immunosuppressive drugs and treatments have expanded the indications for potential recipients. Diseases such as diabetes are no longer contraindications. Previous abuse of alcohol or acetaminophen does not prevent consideration. Age limits are being pushed back. The number of potential candidates is limited only by shortage.

Where have organs come from in the past? The vast majority of organs have come from patients declared brain dead. Brain death presents a clear clinical scenario with objective findings. The American Academy of Neurology has recently again reviewed this subject and the process should be straightforward in any hospital. Brain dead patients are dead, not almost dead or dying. There is no chance for recovery. The persistence of cardiac activity is a physiologic anomaly, not dissimilar to the twitching of a lizard's severed tail. The only legitimate reason for continuing treatment such as mechanical ventilation and intravenous fluids is for the deceased patient's family, surrogate, or proxy to decide on organ donation.

The number of such patients, however, is limited and one of the reasons that the supply and demand problem confronts us. In addition, greater acceptance of living wills has led to discontinuation of life prolonging procedures in many terminally ill patients who formerly might have been kept alive until brain death occurred. Transplant centers, health care providers, government agencies, and hospital ethics committees are struggling with changes in donation protocols to help with alleviating this shortage. The importance of the problem is critical since the appearance of impropriety, conflict of interest, or greater stake in organ harvesting instead of saving the life of the potential donor might unleash a public backlash which ultimately decreases further supply rather than increases it.

What are some of the changes being considered and what are the problems that they present? What does Florida law say about donation? Are there new categories of patients we wish to consider for potential donors?

The first issue to consider is that of informed consent. Consent is, of course, required for any harvesting consideration. The potential donor, however, is rarely in any position to review the usual factors in informed consent: nature of the procedure, risks, benefits, and alternatives. Therefore, health care workers usually turn to families or designated surrogate decision makers for consent. Many patients, though, have already made up their mind about donation and have indicated so on either organ donation cards or their driver's license. These are, in fact, mini advance directives in that they convey what the patient would have wanted if he/she were able to speak for him/herself. Florida law does not require permission or consent if driver's license, valid donor card, or some other advance directive is found. Most hospitals or Organ Procurement Organizations (OPO), however, are unlikely to proceed with donation without at least discussion with family.

The prospect of increasing the donor pool has raised the question of presumed consent. After death occurs, warming or ischemia of the organs causes deterioration and limits their value. One OPO in Illinois felt that the placement of catheters in the femoral blood vessels or abdominal cavity of a recently deceased patient was nondeforming and nonmutilating. Therefore, these procedures could be done without consent for the purpose of prolonging an organ's usefulness until a family or surrogate had time to consider a request for donation. The ethical acceptability of performing invasive procedures on the dead is hardly a settled issue, however. Might a family member or surrogate object to the insertion of catheters which had no bearing at all on the survival of the patient?

Perhaps, an even more critical question, though, is avoiding any confusion over possible conflict of interest: saving the patient's life is clearly the paramount goal. Organ preservation and donation should not enter the thoughts of the treating team, until either death has occurred or the patient's condition is so poor that survival would be impossible. This was relatively simple when all donors were brain dead. A new category of potential donors, however, has emerged:

the non heart beating donor (NHBD). These NHBD patients are usually trauma victims or ventilator dependant patients with some irreversible process (end stage neurologic process or cardiopulmonary disease). The family or even the patient him/herself choose to forgo life prolonging treatment because of futility issues: there is no chance for recovery.

A ventilator patient with amyotrophic lateral sclerosis, spinal cord injury, or muscular dystrophy could potentially ask for withdrawal of life support. These patients are terminal only because the respiratory muscles are no longer able to maintain adequate ventilation. The patient's internal organs might be intact. Most hospitals have protocols for patients to autonomously refuse treatment and withdraw life support when the patient or surrogate feels the burden outweighs the benefit or the quality of life is intolerable. These patients may be mentally intact. Many questions arise from this scenario. Should they be allowed to donate their organs? Should health care workers inform the patient of this option? Should health care workers encourage this option? At what point could preservation catheters be inserted?

The trauma patient presents a different set of disturbing questions. These patients are brought to an emergency department after massive injury and judged not to be salvageable. The critically ill patient and his/her family or surrogate have no prior rapport with the trauma team. Suddenly, they are told there is no chance for recovery and the question of organ donation is raised. Does the narrow time frame in the emergency department provide enough certainty that the previously healthy patient cannot be revived? What safeguards can be made to guarantee that the decision to pursue organ donation did not prematurely end efforts to resuscitate the patient? Should the treating physicians be allowed to participate in the preservation and harvesting procedures? Should the health care team be allowed to bring up the question of organ donation, or should the request emanate from the family or surrogate?

The University of Pittsburgh protocol was one of the first to address these issues with its NHBD protocol. The initial protocol reflected the uncertainty of entering new territory. The protocol stressed that decisions concerning treatment and management of the patients must be made separately from and prior to discussions of organ donation. The consideration of donation could occur only after a decision had been made by the patient, surrogate, or family and physicians that the patient be assigned the status of "comfort measures only." At this point the protocol states that organ donation shall be considered only when the patient or surrogate initiates discussion of organ donation. Trauma patients were not considered eligible for donation. The surgical staff responsible for harvesting must not be involved in the management of potential donors before their death.

The Pittsburgh experience has been sufficiently positive that relaxation in the protocol is planned. Trauma patients will be acceptable for donation and requests must no longer originate with the surrogate.

In Florida the last legislative session moved forward with several changes in the statutes on organ donation. Florida Statute 732.922 requires that hospitals have required request policies so that upon a patient's death the family or surrogate is asked about organ or tissue donation. Statute 732.915 now, however, provides for an organ and tissue donor registry to be set up through driver's license identification and other sources. Inclusion in this registry will constitute consent for donation unless appropriately revoked by the donor.

Another change involves the role of the pronouncing physician. In 732.917 the physician who certifies the patient as dead may participate in the procedure to preserve the donor's organs, but

not participate in the removal or transplanting. This is obviously an important step in non-university hospitals with limited numbers of qualified personnel on site for the purpose of preventing warm ischemia or deterioration of the organs. In teaching centers with many physicians present around the clock, there is sufficient manpower to separate the treating team from any other aspect of transplantation including insertion of the catheters for preservation. In community hospitals, though, there may be no other staff to insert the catheters. The beneficent intention by the patient or surrogate to donate organs that could be preserved would be foiled without this statute. Nevertheless, careful documentation and strict policies will be necessary to assure that the patient received every effort before a decision was made to forgo life sustaining treatment.

The miracle of transplantation and the scarcity of organs should be a dilemma that we all work on solving. Protecting living patients must, of course, be the foremost goal of all health care workers. Organs can only be taken after the patient's death. Strict guidelines that follow consent protocols and respect the autonomous wishes of patients should be followed. But other measures to increase donor supply should include greater public education. Routine inquiry on admission to the hospital could be added to the current checklist of forms and questions. Doctors should include in their office visits questions about patients' preferences on donation with other items such as advance directives, family history, social history, and review of systems. Besides the driver's licence, Veatch at the Kennedy Institute of Ethics has advocated checking off a question about donation on the income-tax return.

The importance of meeting this challenge is obvious to all who have known or cared for the recipient of a transplant. Our failure could result in the loss of public trust and decrease in donations as we enter an era when we can technically do more than ever.

Selected References

- 1. Spital, A. The shortage of organs for transplantation. NEJM. 1991; 325: 1243-1246.
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- 3. Younger, SJ, Arnold, RM. Ethical, psychosocial, and public policy implications of procuring organs from non-heart-beating cadaver donors. JAMA. 1993; 269: 2769-2774.
- 4. Caplan, AL. Current ethical issues in organ procurement and transplantation. JAMA. 1994; 272:1708-1709.
- 5. Spital, A. Mandated choice: a plan to increase public commitment to organ donation. JAMA. 1995; 273: 504-506.

WELCOME NEW MEMBERS!

The Florida Bioethics Network welcomes William Allen, Chaplain, Winter Haven Hospital, Winter Haven ~ 941/293-1121 x1877; Maxine Anastasia, Nurse Manager ICU/PCU/ER, South Seminole Hospital, Longwood ~ 407/767-5831; Arthur Berger, Director, International Institute for Study of Death, Miami ~ 305/936-1408; Edna Clifton, Consultant, Contract with Hospice, St. Petersburg ~ 813/898-0904; Sue Felber, Medical Librarian, Naples Community Hospital, Inc., Naples ~ 941/436-5383; Denise Heinemann, RN Coordinator, University of South Florida, Fort Myers ~ 941/432-5561; Anne Iuliano, Health Care Risk Manager, Naples Community Hospital, Inc., Naples ~ 941/436-5009; Geoffrey Maul, Interim Cardiopulmonary Director, South Bay Hospital, Sun City Center ~ 813/634-0116; Michael Morgan, Licensed Clinical Social Worker, University Medical Center, Jacksonville ~ 904/399-4831; Dr. Mervin Needell, Medical Director, Forum for Bioethics, University of Miami School of Medicine, Miami ~ 305/243-5723; Dr. Sandra Overstake, Associate Chief, Nursing Services, Bay Pines VA Medical Center, Bay Pines ~ 813/398-6661; Susan Reynolds, Senior Health Planner, Health Council of South Florida, Miami ~ 305/273-9020; Dr. Michael Walker, Bay Medical Center, Panama City ~ 904/769-3261; Dr. Charles Weitzel, Chairman, Ethics Committee, Columbia Brandon Regional Medical Center, Brandon ~ 813/684-8674.

ITEM OF INTEREST

We have available cassette tapes from the FBN Annual Meeting on September 20-22, 1995, in Tampa. If you are interested in a copy of these tapes, please contact **Luanne MacNeill** at FHA ~ 407/841-6230 x106 for further information.

ESSENTIAL READINGS #4

Submitted by **Francille MacFarland, MD,** Winter Park.

Principles and Theories in Medical Ethics:

- 1. Arras, J.D. Getting Down to Cases: The Revival of Casuistry in Bioethics. Journal of Medicine and Philosophy 1991; 16 (1): 29-51.
- 2. Beauchamp, T.L., Childress, J.F. <u>Principles of Biomedical Ethics</u>. Oxford University Press, N.Y. 1994.
- 3. Beauchamp, T.L. Principlism and Its Alleged Competitors. Kennedy Institute of Ethics Journal 1995; 5 (3): 181-198.
- 4. Carson, R.A., Callahan, S. et al. Spirit, Emotion, and Meaning: The Many Voices of Bioethics. Hastings Center Report 1994; 24 (3): 26-27.
- 5. Clouser, K.D., Gert, B.A. A Critique of Principlism. Journal of Medicine and Philosophy 1990; 15 (2): 219-36.
- 6. Clouser, K.D. Common Morality as an Alternative to Principlism. Kennedy Institute of Ethics Journal 1995; 5 (3): 219-36.
- 7. DuBose, E.R., Hamel, R.P. et al. <u>A</u>
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 <u>Bioethics</u>. Trinity Press International, Valley
 Forge, PA 1994.
- 8. Jonsen, A.R., Toulmin, S. <u>Abuse of Casuistry: A History of Moral Reasoning</u>. University of California Press, Berkeley, CA 1988.
- 9. Koppelman, L.M. Case Method and Casuistry: The Problem of Bias. Theoretical Medicine 1994; 15 (1): 21-37.

- 10. O'Neill, W.R. The Ethics of Our Climate: Hermeneutics and Ethical Theory. Georgetown University Press, Washington, DC 1994.
- 11. Pellegrino, E.D., Thomasma, D.C. <u>The Virtues in Medical Practice</u>. Oxford University Press, NY 1993.
- 12. Pellegrino, E.D. The Metamorphosis of Medical Ethics: A 30-Year Retrospective. JAMA 1993; 269 (9): 1158-62.
- 13. Salaberry, P.J. Caring, Virtue Theory, and a Foundation for Nursing Ethics. Scholarly Inquiry for Nursing Practice 1992; 6 (2): 155-67.

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Hesse, K.A. Terminal Care of the Very Old: Changes in the Way We Die. Archives Internal Medicine 1995; 155: 1513-18.

Pellegrino, E.D. Toward a Virtue-Based Normative Ethics for the Health Professions. Kennedy Institute of Ethics Journal 1995; 5 (3): 253-77.

Tomlinson, T., Czlonka, D. Futility and Hospital Policy. Hastings Center Report 1995; 25 (3): 28-35.

Veatch, R.M. Resolving Conflicts Among Principles: Ranking, Balancing, and Specifying. Kennedy Institute of Ethics Journal 1995; 5 (3): 199-218.

MEETING CALENDAR

Regional Meetings

- ♦ March 8-9, 1996: The University of Miami Forum for Bioethics and Philosophy announces the 4th Annual Conference ~ "Clinical Ethics: Debates, Decisions, Solutions" in Miami, Florida. This program includes expert panel discussions on ethics and managed care and institutional futility policies, and popular moderated round table discussions on managed care and futility. Topics of discussion include:
 - ✓ Patient Advocacy Under Managed Care: A Hands-on Approach
 - ✓ Presymptomatic Genetic Testing: Ethical & Psychological Issues
 - ✓ JCAHO Requirements for Ethics Committees
 - ✓ Establishing Education Programs for Ethics Committees
 - ✓ Dilemmas in Prediction
 - ✓ Business and Organizational Ethics in Health Care
 - ✓ Domestic Violence: Ethical, Social, and Legal Issues
 - ✓ The Regional Futility Survey
 - ✓ Should Institutions have Futility Policies?
 - ✓ Introduction to Decision Making in Bioethics

For more information on this meeting, call or write: Forum for Bioethics & Philosophy, University of Miami, P.O. Box 016960 (M-825), Miami, FL 33101, Tel: 305-243-5723; Fax: 305-243-5819; e-mail: ethics@mednet.med.miami.edu

- ♦ April 26-28, 1996: Ethical Issues in Dialysis, Transplantation, and Long-Term Life Sustaining Treatment; Rolling Hills Hotel & Golf Resort, Ft. Lauderdale, FL; Contact: Dr. Jos V.M. Welie, CEREC Center, P.O. Box 292932, Ft. Lauderdale, FL 33329. Tel./Fax: 305/424-9304. E-mail: jewlie@bcfreenet.seflin.lib.fl.us.
- August 23-25, 1996: Ethical Issues in the Care of Incompetent Patients; Rolling Hills Hotel & Golf Resort, Ft. Lauderdale, FL; Contact: Dr. Jos V.M. Welie, CEREC Center, P.O. Box 292932, Ft. Lauderdale, FL 33329. Tel./Fax: 305/424-9304. E-mail: jewlie@bcfreenet.seflin.lib.fl.us.

National Meetings

♦ February 29-March 3, 1996: Association for Gerontology in Higher Education holds its 22nd annual meeting, "Beyond the Rainbow: Diversity and Collaboration," in Philadelphia, PA. Contact: 202/429-9277.

International Meetings

- ◆ July 28-August 1, 1996: 11th World Congress on Medical Law; Sun City, South Africa. Contact: Congress Secretariat, International Centre for Medicine and Law, 51 Buhrmannsdrif 2867, South Africa. F: 27-140-24894.
- ♦ August 17-22, 1996: International Association for the Study of Pain (IASP) holds "8th World Congress of Pain" in Vancouver, British Columbia. Contact: IASP Secretariat, 909 N.E. 43rd Street, Ste. 306, Seattle, WA 98105; or 206/547-6409; F: 206-547-1703.
- ◆ August 23-28, 1996: Xth World Congress of Psychiatry; Madrid, Spain. Contact: Ellen Mercer at 202/682-6286; F: 202-789-8882.
- March 4-7, 1997: Barry University School of Podiatric Medicine presents "Foot and Ankle Surgery Symposium 2000-3000," 15 CME credits pending; Jerusalem, Israel. Contact: Madeline Reforgiato, 800/319-FEET or 305/899-3266 or Cristal Rochester, 305/899-3255. Official Symposium Travel Agency: Charles Hannon & Associates ∼ 800/701-4090.