

*Health Care Law*

*Mid-Atlantic Ethics Committee Newsletter*

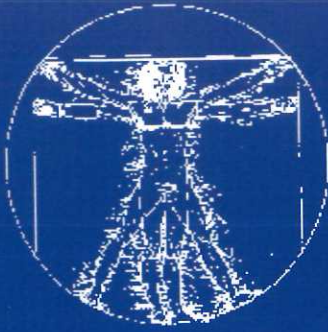
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University of Maryland Francis King Carey School of Law    *Year 1998*

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Mid-Atlantic Ethics Committee  
Newsletter, Spring 1998

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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

Spring 1998

## MORAL MUSINGS: THE "VIRTUOUS" BIOETHICIST?

In November, a joint Task Force of the Society for Bioethics Consultation (SBC) and the Society for Health and Human Values (SHHV) presented a proposal at a national conference in Baltimore on standards for conducting health care ethics consultations. (*See article page 4.*) Incorporated into the standards were suggestions for the types of skills, knowledge and *character* traits that are important for conducting ethics consultations. While the need for certain skills and knowledge is easy to understand, the idea of a national task force setting out character traits or "virtues" that individuals conducting ethics consultations should possess is a different matter. However, after brief reflection I realized that "good character" is not an unusual requirement for entry into other professions. For example, physicians and many other health care providers wishing to receive a license in many states must be of "good moral character," although there is generally a fairly low threshold for what counts as "good character." For example, in Maryland, the good moral character requirement for physicians is operationalized in large part by sending out a form called "Attestation to Applicant's Good Moral Character" to two individuals who have known the applicant for more than five

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### Letter From the Editor

This issue of the newsletter focuses to a large extent on the recently proposed standards for ethics consultations put forward by a Task Force of the Society for Health and Human Values. As always, we also report on the many activities of the area Networks. These Networks appear to be healthy and flourishing. This issue's case and commentary are devoted to a home health agency case involving a child who is the victim of a drowning incident. I hope you find the issue of interest. Please don't hesitate to submit comments or ideas for future issues!

Diane E. Hoffmann

years and are not related to him or her. The form simply requires the references to inform the Board of any knowledge they have of the applicant's arrests, convictions, or loss of privileges to practice medicine.

The recommendation of the Task Force sets a much higher standard and is consistent with the field of "virtue ethics." Most ethical theories speak to

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## NETWORK NEWS

### Maryland Health Care Ethics Committee Network (MHCECN)

The Maryland Health Care Ethics Committee Network has been engaged in several activities as it begins to reform and revitalize the organization that was formerly known as the Baltimore Area Ethics Committee Network. By-laws for the MHCECN are being written, a membership drive is being planned, and the education subcommittee is involved in planning several educational talks, in addition to an early summer and fall workshop. In conjunction with the University of Maryland Law and Health Care Program, the Network has been awarded a planning grant by the Greenwall Foundation. (See article page 6.) J. Anne O'Neil, PhD, RN has recently come on board to coordinate the grant study and assist Diane Hoffmann, JD, a member of the Executive Board, with other Network efforts. Other recent activities of the Network include: a continental breakfast at the November Society for Health and Human Values Conference in Baltimore, co-sponsored with the Masters Program in Applied and Professional Ethics at the University of Maryland Baltimore County, and a brief meeting and get-together following the University of Maryland Medical System's Humanities Hour in February. For further information on the MHCECN or a membership application, contact Diane Hoffmann at (410) 706-7191.

### Virginia Center for Biomedical Ethics (VCBE)

The Virginia Center for Biomedical Ethics has issued a call for papers addressing the relationship of business ethics, clinical ethics, and professional ethics within the context of organizational constraints for a National Conference on "Organizational Ethics and Health Care," to be held in September.

Papers that address the relationships between two or more of these perspectives are of particular interest. The deadline for submission is May 1, 1998. For more information, contact Patricia Werhand, PhD at (804) 924-4840 or Mary Rorty, PhD at (804) 982-4227.

Dr. Edward Spencer, Director of Outreach Programs at the Center for Biomedical Ethics has advised Developing Health Care Ethics Programs (DHEP) Fellows that the format of the program will change slightly. One full day will be devoted to "organization ethics." DHEP is a six day course presented by the Center for Biomedical Ethics offering a course of study for health care professionals from hospitals and other health care institutions. The change in the program is being made in response to a growing concern over the implications of the JCAHO's 1995 requirement that healthcare organizations implement an "organization ethics function." Dr. Spencer is inviting up to 15 previous DHEP participants to attend the session. Please call (804) 982-3978 if you are a previous Fellow and require more information.

### Washington Metropolitan Bioethics Network (WMBN)

The Washington Metropolitan Bioethics Network joined the Washington Metro GenEthics Consortium in January to hold a program featuring a case discussion about the ethical considerations of genetic testing and the effects of testing on individuals and families. The moderator was Robert Murray, M.D., from Howard University with presentations given by Gail Geller, M.D., from Johns Hopkins University and Sulayman Nyang, M.D., from Howard University. The case involved a man with a significant family history of a certain cancer whose family members undergo genetic testing to identify gene mutations which create susceptibility to this disease. The case discussion focused

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**The "Virtuous" Bioethicist?**  
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actions of individuals or groups. Virtue ethics speaks to the underlying character of the individual making a moral choice or taking action in a morally problematic situation. It is the agent him or herself who is the focus of this theory. Virtue/character theories come to us from the philosophy of Plato and Aristotle. Moral virtues are those virtues that are valued by a society when humans face moral conflicts. It is not the person who performs a morally "right" action that is thought of as virtuous. The virtuous person must also have a value system that guides him to performing the right action for the right reason. We ask of others, or ourselves "What is their/my inner motivation for this choice?" An ethicist who guides his actions by what benefits him/herself may indeed stand up for patient autonomy during an ethics consultation. However, his or her reason may have more to do with the patient's making a decision the ethicist agrees with than a belief that patient autonomy is of high moral value.<sup>1</sup> Mother Theresa is often mentioned as a person we look to as morally virtuous. Not that her actions were always considered sound and correct, but rather that we never doubted that she was a "good" person whose motivations were sound and correct. While virtue ethics has not played a significant role in medical ethics, it has recently gained popularity in the lay community. Elementary and secondary schools now offer courses in character and Bill Bennett's *Book of Virtues* has become a best seller.

The Task Force proposal states specifically that "[g]ood character, valuable for all persons who work in health care, is important in unique ways to persons who perform ethics consultation." The proposal suggests the following characteristics as important to those performing ethics consultations: patience, fairness, tolerance, compas-

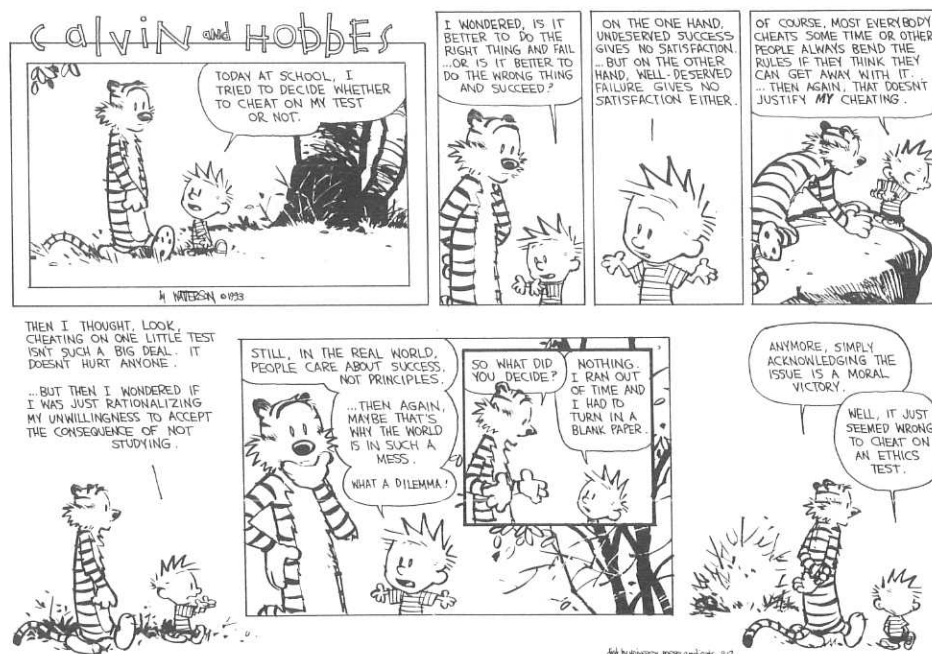
sion, honesty and forthrightness, integrity, courage, and prudence. These traits seem to go much farther than those required for physicians and other health care professionals, at least as a matter of licensing. But perhaps that is not the appropriate comparison. Perhaps the more appropriate way to think about these traits is to ask why they are necessary or especially important in the context of ethics consultation. One response is that because ethics consultation is a new field, those establishing themselves or calling themselves bioethicists need to be especially "good people" in order not to sully the reputation of the fledgling profession. This is important for establishing the credibility of the profession in the eyes of the public. But, perhaps, more importantly, is the need to be credible and effective with health care providers, patients and family members within the institution where the consults are being performed. We are less likely to seek help or assistance from someone whom we don't respect as a person than from someone we look up to and value as a person. Also, it seems that there is something about advising on matters of "ethics" that as a matter of common sense requires a person of high ethical standards. The latter point reminds me of the Calvin and Hobbes cartoon in which

Calvin is debating whether to cheat on an exam. After some self reflection, he decides that it certainly would not be ethical to cheat because it is an ethics exam.

Finally, as I thought more about this issue, I remembered a discussion we had when I sat on the ethics committee at the NIH Clinical Center when we were trying to choose a chair or co-chairs of the committee. Jan Vinicky, who was at the time on the staff at the NIH Office of Bioethics, suggested the following characteristics that we might consider in selecting a chair:

- ◆ humility
- ◆ open-mindedness
- ◆ willingness to learn
- ◆ ability to sublimate own values and be open to other's values
- ◆ ability and willingness to work cooperatively with multidisciplinary groups
- ◆ ability to refrain from knee-jerk decision-making
- ◆ critical thinker capable of reflective thought and logical analysis
- ◆ interest and motivation necessary to motivate others

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## The "Virtuous" Bioethicist?

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- ◆ commitment to the field and to the endeavor
- ◆ knowledge of limitations and
- ◆ willingness to get help

While this list might appear to be only attainable by the saints, it seems to me that these are qualities worth looking for in any ethics committee member, especially those conducting ethics consults. Without virtuous ethics committee members, health care providers and health care institutions are unlikely to respect the committee or its members. This is not to say that we don't want individuals who make mistakes or who have had some troubled spots in their lives or careers but only that we want individuals who can admit their mistakes or rise above their past and can command respect from those with whom they deal on a regular basis.

By Diane Hoffmann, MS, JD  
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<sup>1</sup>Beauchamp, T.L. & Childress, J.F. (1994). *The Principles of Biomedical Ethics* (4th ed). New York: Oxford University Press, (62-69)

## Network News

Cont. from page 2

on the stress induced by this process and the resulting emotional turmoil and fracturing of intra family relationships due to among other things, searching for the extended family member who introduced the gene. The discussion also included the patient's own reflection, after experiencing his own personal struggle, about whether society is ready for this type of testing.

The Network also participated in a program in December focusing on the British video, "Selling Murder," which illustrates the Nazi propaganda in the 1930s involving the medical profession. Panelists and the group discussed the

relevance of the topic to today's debate about assisted suicide and euthanasia, as well as the issues of cost and care. The Washington Network suggests this video to other Networks for use in ethics committee discussions.

## West Virginia Network of Ethics Committees (WVNEC)

The West Virginia Network of Ethics Committees will hold its Eleventh Annual Symposium on May 15, 1998 (see *Calendar*). The theme will be "Working With Difficult Patients, Difficult Families, and Difficult Payors." This program will focus on medical, ethical, legal, and psychosocial issues in the new health care climate in which patients, families, and payor often have different values and different expectations of each other. The format of the symposium will emphasize interaction among all participants, and the symposium will include separate break out sessions for those working in the hospital, nursing home, and home care-hospice settings. For more information please call the WVNEC office at (304) 292-7618.

## Richmond Bioethics Consortium (RBC)

In 1997, the Richmond Bioethics Consortium (RBN) held quarterly meetings to discuss the issue of futility as it related to the delivery of medically inappropriate treatments, especially at the end of life. These meetings are continuing into 1998 on a bi-monthly basis and will consist of two subgroups: one focusing on policy and the other on community dialogue.

The opening lecture topic, presented by Edmund Pellegrino Sr., M.D., for the Georgetown Center for Clinical Bioethics and the Bon Secours Richmond Ethics program was "Medical Ethics: An Ancient Discipline and a New Millennium." The lecture presented on January 20, 1998 also marked the first class of the Bon Secours Richmond Ethics Program.

Other updates: Currently RBC is exploring the possibility of academic

alliances with area institutions of higher learning to provide expanded areas of educational opportunities, and is busy planning public educational offerings for 1998. Keep an eye on the calendar for topics and speakers!

## STANDARDS FOR BIOETHICS CONSULTATION

In November, a Task Force composed of members of the Society for Bioethics Consultation and the Society for Health and Human Values unveiled their proposal for standards for conducting bioethics consults at the joint meeting of the American Association of Bioethics, the Society for Bioethics Consultation, and the Society for Health and Human Values in Baltimore, MD. The Task Force included 21 scholars in the fields of health care ethics, health care and health policy and included professionals with backgrounds in medicine, nursing, law, philosophy and religious studies. The Task Force effort was funded primarily by a grant from the Greenwall Foundation but the effort also brought contributions from other organizations, centers and networks. The work of the Task Force was motivated by "the belief that those who offer ethics consultation have an obligation to work to ensure that when patients, health care providers, or others request their assistance in resolving ethical conflicts or uncertainties, they are competent to offer that assistance." At least one source also noted that the general concern about competence of ethics consultants in part stems from some "recent legal cases" where there was "input from 'ethics consultants' who turned out to have had little or no training in ethics."

The Task Force report has five parts:

1. Health Care Ethics Consultation: Nature and Goals
2. Health Care Ethics Consultation: Core Competencies
3. Health Care Ethics Consultation: Organizational Ethics
4. Health Care Ethics Consultation: Importance of Evaluation

## 5. Special Obligations of Ethics Consultants and Institutions

The bulk of the report is devoted to the core competencies that those doing ethics consults should possess. While clearly the report is an effort to set minimal standards for competency in this new and growing field, the Task Force takes a strong position that these standards should only be used on a voluntary basis and should not be used as a basis for certification of bioethicists or those conducting ethics consults by a bioethics society or other independent certifying agency; nor as a basis for accrediting educational programs training individuals in bioethics. Reasons the Task Force provides for rejecting this use of its standards include the possibility that certification might become associated with a particular discipline, e.g. clinical medicine, preventing those from outside that discipline from becoming certified; certification might give the impression that those conducting consults are substantive moral experts that can provide "the answers" to difficult ethical problems; certification could have divisive ramifications for the bioethics community; it would be difficult to design a standardized test to measure the competencies necessary to perform bioethics consults; certification would require the development of a new bureaucracy to manage it; and certification has the potential to "disenfranchise large numbers of individuals currently active in the field" who may be unable to satisfy the rigor of a certification process.

As regards accreditation, the Task Force rejects this use of the standards for a number of reasons but most persuasively because it could have an adverse effect on the disciplinary diversity of those performing bioethics consults and because the model requires a significant administrative infrastructure.

The section of the report on "core competencies" is prefaced with important definitions and clarifications of what ethics consultation is, the issues that those conducting ethics consultation must be prepared to address, the context in which these issues emerge, possible

models of ethics consultation, and the goals of health care ethics consultation. This latter clarification is particularly helpful. The report states that the general goal of health care ethics consultation is to:

"improve the provision of health care and its outcome through the identification, analysis and resolution of ethical issues as they emerge in consultation regarding particular clinical cases in health care institutions."

Core competencies necessary for performing ethics consultations include core skills of ethical assessment and process and interpersonal skills, as well as core knowledge areas. The latter includes knowledge of moral reasoning and ethical theory, knowledge of common bioethical issues and concepts, knowledge of health care systems and clinical terminology, of codes of ethics and relevant health law, and familiarity with the values and operations of the institution within which one is performing consults as well as with the beliefs and perspectives of the institutions' patient and staff population. The reports lays out in some detail the types of skills and knowledge necessary under each of these general categories. In core competencies, the report also lists important character traits of those performing ethics consults. (*See article, page 1.*)

The Task Force also takes a tentative stab at addressing organizational ethics consultation, pointing out that "as the delivery and financing of health care has been increasingly centralized in health care systems that serve defined populations, and as cost containment has become a national concern, the important relationship between bedside and board room has become inescapable. . . [and that] ethics consultants will increasingly be unable to provide consultation services to one area while ignoring the other." While this topic is included in the Task Force report it is the most undeveloped area of the Task Force's thinking, most likely because it is an area still in its infancy with which few bioethicists have had extensive experience.

Finally, the Report addresses the importance of evaluation as a tool to

improve ethics consultation and the special obligations of ethics consultants and institutions. This latter section addresses the issue of abuse of power and conflict of interest of those performing ethics consults and institutional obligations to those who provide and utilize ethics consultation services. The Report urges that institutions support those performing ethics consults by providing them with 1) the resources they need to perform consultations competently, 2) adequate time and compensation; and 3) an environment in which those who are performing ethics consultations "can carry out their work free of concerns about job security, reprisals or undue political pressures."

The Task Force draft proposal is available on the Internet at the following website: <http://www.mcw.edu/bioethics/ddcov1.html>.

## METROPOLITAN WASHINGTON NETWORK COLLABORATES WITH D.C. COURTS ON GUARDIANSHIP CASE

On November 13, 1997, the Metropolitan Washington D.C. Bioethics Network presented, "Increasing Access to Justice: Bioethics Consultations in Guardianship Matters and Medical Emergencies." The presentation involved six panelists who discussed the Network's pilot program which provides volunteer bioethics advisory panels for guardianship and medical emergency cases before the D.C. Superior Court. The panel consisted of organizers and participants, including The Honorable Cheryl Long, Judge D.C. Superior Court; Joan Lewis, Coordinator, Metropolitan Washington Bioethics Network; John J. Lynch, M.D. advisory panel leader; Vera Mayer, Esq., advisory panel leader; Andrea Sloan, R.N., J.D., advisory panel leader; and Renee Fox, Esq., guardianship attorney.

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## Metropolitan Washington Network Collaborates With D.C. Courts

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### History

The bioethics advisory panel pilot program, which began in April 1997, is the only such program in the United States, according to Joan Lewis. The project started after a group of hospital, nursing home, and senior center representatives expressed a desire for more dialogue between the medical and legal communities regarding identifying the need for guardianship and making decisions for patients in medical emergencies.

Judge Long identified the two types of cases where the court is most likely to request an advisory panel: 1) a petitioner asks to be appointed as general guardian for a disabled person who is suffering from Alzheimer's disease or a head injury, or is retarded; and 2) a hospital asks to be appointed temporary guardian in order to make decisions about emergency medical care for a patient. Judge Long explained how the advisory panels help the judges by providing information that judges otherwise would not have.

### How Advisory Panels Are Appointed

In the D.C. Superior Court, judges rotate being on call in case of emergencies. Judge Long said that whether an advisory panel is requested depends somewhat on which judge is presiding. When a judge believes that more factual information or advice on complicated bioethical issues is needed, the judge calls for an advisory panel consultation. Judge Long estimates that judges make approximately three appointments per month to an advisory panel. She also notes that many of the consultations are not "bioethical," but address difficult medical-legal issues. The consultations provide objective fact-finders who have the time to conduct an in-depth investigation.

### How the Panels Function

Once a judge determines that an advisory consultation is needed, she

calls one of the three panel leaders. Each leader has a list of ten to twenty volunteers who were assigned to one of the three groups. The group leader then calls members of her group to find at least three people who are available to advise on this case. Typically the leader tries to secure participation from volunteers with different backgrounds, each of whom can contribute from their own perspective, using their expertise. For example, the leader convenes an advisory panel composed of a physician, lawyer, and social worker. These three volunteers then discuss what needs to be done and assign responsibilities.

Member responsibilities commonly include interviews of the patient or alleged disabled person, family members, neighbors, health care providers, and religious advisors. After gathering information, the panel members share what they've learned and discuss the issues. Finally, the panel recommends a course of action which the court may adopt, alter, or disregard. Both Judge Long and numerous participants noted the value of the panels by anticipating future needs of patients and incorporating these expectations into any recommendation.

### An example

As reported by one nurse/lawyer who participated on an advisory panel, a judge requested the panel's opinion on the competence of a female who had been financially exploited. The judge had been asked to name a guardian to oversee the woman's financial affairs, yet believed that more information would help with the decision. Panel members conducted interviews of the woman, her family members, and her court-appointed attorney. After gathering information, the panel members discussed both the facts and the woman's needs, and finally recommended a limited guardianship.

### What is Next

At the close of the meeting, both panel members and audience participants discussed the value of a Quality Assurance mechanism, and a manual that would advise other courts and ethic

committees who might be interested in adopting a similar program. Both of these ideas will be discussed and investigated.

by Colleen S. Hogan, MBA, MHA  
JD Candidate

University of Maryland School of Law

## LAW & HEALTH CARE PROGRAM AND MARYLAND NETWORK RECEIVE GREENWALL FOUNDATION GRANT

Motivated by the ongoing debate about the qualifications necessary to sit on an ethics committee or to perform ethics consults, the University of Maryland Law School's Law & Health Care Program, in coordination with the Johns Hopkins Bioethics Institute and Maryland Health Care Ethics Committee Network applied to the Greenwall Foundation and received a grant to assess the educational background, knowledge and skills of individuals in Maryland currently performing bioethics consults as part of ethics committees. The study results will indicate whether those currently performing consults have many of the "core competencies" recommended by the Task Force on Standards for Bioethics Consultations. (*See article, page 4.*) The survey is currently in the process of being developed and will be sent out to hospital ethics committee chairs in the state later this spring. For more information about the study please contact Diane Hoffmann at (410) 706-7191.

# Case Presentation

*One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee 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 Study From a Maryland Home Health Agency

One day last summer, two-year-old Joey was running around his family's pool. Unfortunately, no one noticed when he fell in. Some five to ten minutes later he was discovered floating face down in the clear warm water. Pulled from the water he was wet, bluish and did not respond to his mother's pleas to wake up. His mother began CPR and his father called 911. He was taken to the nearest community hospital. After being stabilized, he was flown to a local academic hospital where he spent two months for stabilization and intensive rehabilitation. Finally he was sent home. The official diagnosis was "anoxic brain injury status post near drowning." To his parents this meant they no longer had a healthy little Joey, but a new Joey who lies listless in his crib and does not respond to his parent's voices or touch. Although not on a ventilator, he has periods where his breathing stops and he must be "bagged" by someone in order to restart his breathing. He is also

subject to bouts of pneumonia, must be fed through a tube in his stomach and have all his other bodily needs taken care of by others. At this time, his insurance is paying for 16 hours a day of home nursing care. How long they will continue this level of nursing support is not known. His mother works and it is her insurance that covers Joey's care. Joey's father farms the family acreage. The nurses from the home care agency are beginning to establish their presence in the home. They have noted Dad standing in the doorway of Joey's room, but they have not seen him pick Joey up or help with his care. Joey's Mom is very tired. She works during the day and then takes over Joey's nighttime care. Three nurses have been caring for Joey for almost a month now, but have had only brief conversations about Joey and his future. Mom is always on the run and Dad is evasive when it comes to talking about Joey's care. Most conversations have been brief reports from Mom on the events of the previous night. Mom has stated that she expects him to get better and she can see signs that Joey is beginning to respond to her voice. She says she has seen him move his toes when she asked him to. She does not want to speak to the possibility of his dying or to make him a no code. The nurses have not noticed any purposeful movements or change in his condition. The nurses are beginning to feel conflicted about their responsibilities. What are they to do when the time comes that bagging Joey will not restore his breathing or his heart stops and further action is needed? His doctor's orders state that they may establish an airway and call 911; that if his heart stops they may start an IV and give fluids and medications; that they are not to do any chest compressions to start his heart again. However, attempt-

to start an IV and give emergency medications while Joey is in respiratory and cardiac arrest would be difficult if not impossible. When Joey is under stress he "postures" and curls into a tight fetal position. How does the lone nurse start an IV? The nurses are concerned that they are being placed in an untenable position and will be unable to effectively assist Joey in a crisis situation. All they will be able to do is stand by and watch him die. The home health agency is concerned for their liability if Joey should die and his mother is left with feelings that he might have been spared if nursing had only done something. What are the ethical questions inherent in cases like this? How can an ethics committee assist in resolving this situation?

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*"Although he lies listless in his crib and is dependent on others to keep him alive, at times Joey's mother perceives that he responds to her voice."*

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## Case Discussion: Comments From a Home Health Nurse

One can only imagine the horror of losing a child to a drowning. Parents are faced with the task of reconciling any feelings of guilt at not having protected their child from harm. This complicates the already painful grieving process that follows the death of a child. In this case, the parents lost the child they knew—their previously healthy two-year-old Joey is replaced with an unresponsive Joey. The parents' recognition and expression of their grief over this loss seems to be thwarted, possibly because their attention is focused on hopes for Joey's recovery. Although he lies listless in his crib and

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## Case Discussion

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is dependent on others to keep him alive, at times Joey's mother perceives that he responds to her voice. Perhaps she is not willing to repeat her perceived transgression of abandoning him when he fell into the family's pool. Isn't it a parent's job to favor hope for a child's recovery over grief at his loss?

There are many ethical questions inherent in cases like this. What obligations are owed to Joey? To Joey's parents? To the nurses taking care of Joey in his home? Obligations to Joey include assessing his potential for improvement and the quality of his present and future life, and providing him with the care he needs in order to maximize his potential and minimize his suffering. With pediatric home care cases, it is especially evident that the "patient" encompasses the family as a whole. Therefore, obligations exist not only to Joey, but also to Joey's parents. Nurses' observations of the dad's distancing from Joey and mom's fatigue and evasion of discussing Joey's future, should serve as red flags that the parents are likely in need of support and professional guidance. Lastly, the nurses caring for Joey deserve to be included in discussions of plans for life-sustaining medical interventions. What informed Joey's physician in the decision to allow bagging and the use of emergency medications in the event of cardiac arrest, but to withhold chest compressions should Joey's heart stop beating? How should decisions about life-sustaining therapy that are made by pediatricians and parents be communicated with other members of a treatment team, especially when nursing care is provided by a home care agency?

While it is important in Joey's case to know facts, such as medical prognosis, degree of brain function, whether or not Joey feels pain or suffers, etc., parents need to reconcile facts with emotions as they make important decisions. Effective communication at such times is critically important. It is stated that Joey's nurses "are beginning to establish their presence in the home." Are they also beginning to establish a

relationship with Joey's mom and dad? Is any one nurse of the three closer to either of Joey's parents? Could that nurse take the lead in following up on the "red flags" that were mentioned earlier? Could a care conference be scheduled with the physician, nurses, and parents (and anyone else involved in Joey's care) to facilitate such communication?

Individuals caring for children like Joey experience a range of responses. For some nurses Joey's physical care may overshadow larger issues, such as the parents' styles of coping with Joey's chronic debilitation and possible vegetative state or death. Other nurses may focus on the atypical "no-chest-compressions" order (in the absence of a do-not-resuscitate or "DNR" order) and feel conflicted about how they would respond in a medical emergency. It is the physician's obligation to write clear orders regarding life-sustaining treatment, and to clarify those orders with the patient's case managing nurse. The physician may not be aware that it could be more difficult for a home health nurse to start an IV in Joey if he were posturing than it would be to attempt chest compressions were Joey's heart to stop beating (although this, too, would be difficult if he was curled into a tight fetal position). If the physician fails to properly write and communicate clear orders regarding life-sustaining treatment, the nurse overseeing Joey's care (his "case manager") should clarify orders with the physician. The parents' decisions about life-sustaining emergency interventions for Joey may change over time. Establishing a forum for communication between Joey's parents, the nurses, the physician (and anyone else involved, e.g., a spiritual counselor or chaplain) would allow for needs, preferences, and medical facts to be communicated to the parents and all members of the treatment team.

Some health care providers may dismiss hopes for a meaningful future for a child like Joey because they have experienced poor outcomes with similar children. They see an unresponsive, brain-damaged child lying in a crib and wonder, what's the point? What are we really doing here? Yet parents often see

the child who was and the child who still could be. They have memories of the child surrounded by emotions of love, regret, happiness and deep sorrow. Often times, simply acknowledging these memories and emotions can initiate meaningful dialogue. What was Joey like before his accident? What were his parents' hopes and dreams for him? What are their hopes for him now? How might they cope if these hopes are not realizable? Whether such a conversation takes place in the context of a care conference or between a nurse and Joey's mom or dad, acknowledging emotions and hopes as well as medical "facts" should help the parents realize that health care providers want what is best for Joey and his parents. If Joey's mom insists on leaving the "without chest-compressions" order as it was written, what then? A physician is not obligated to order care that cannot feasibly be implemented. Health care providers should find a way to provide care for Joey and his parents that does not conflict with their professional duties. Contingency plans should be discussed in advance with the goal of minimizing future regrets for all involved while attempting to act in the best interests of the family as a unit. Empathy, open-mindedness, imagination, and most importantly, careful communication should help accomplish those goals.

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## Case Discussion: Comments From a Pediatric Intensivist

The case of Joey, a two year old with hypoxic ischemic encephalopathy (HIE), focuses our attention on issues regarding surrogate decision-making for the pediatric patient. An understanding of the natural history of HIE in the child is essential to developing an ethical approach to Joey's family and to his health care providers. The life expect-

ancy for Joey is significantly curtailed due to his severe degree of brain injury. Joey has no evidence of higher brain (i.e. cortical) functioning, and even his brainstem seems impaired as evidenced by his episodes of apnea. The natural history of Joey's disease includes progression from his current dependent state to frequent episodes of aspiration pneumonia with or without respiratory failure, requiring repeated hospitalizations at an acute care facility. The time course may be months to years, but a downhill course is inevitable for this severely impaired child.

With frequent aspiration pneumonia in their children, some parents opt for a surgical anti-reflux procedure to eliminate aspiration of gastric contents. These children receive nutrition only from their gastrostomy tubes, as the risk of primary aspiration from oral feedings is too great. Thus, any pleasure the child had received from oral feedings would have to be sacrificed. Finally, some parents opt for surgical placement of a tracheostomy tube, to allow a safe airway for suctioning and access for bagging and/or mechanical ventilation during episodes of pneumonia.

After the goal of excellent medical care for Joey, the most important role for the health care providers is helping to educate Joey's parents regarding his current condition and prognosis. His parents must be in a position to make informed decisions as Joey's surrogates. This education should include an honest discussion of the natural history of Joey's encephalopathy. More than two months following the near drowning event, it is unequivocally clear that Joey will never walk, talk, or probably even smile. In fact, he may well be at his maximal developmental state at this time.

The first step towards placing the parents in a position to be the best surrogates for Joey is to have a "family meeting" that should include the parents, Joey's primary health care provider, those nurses who have been involved in his home care, and a neurologist or developmentalist. Joey's pediatrician and his nurses, in addition to supplying the information regarding Joey's current status, should also be

encouraged to have any questions they have regarding Joey's prognosis answered by the neurologist. Only with adequate and real information can an individual expect to be able to advocate for a child.

The health care team needs to allow the parents time to assimilate and internalize the knowledge regarding their son's grim prognosis. Two months may simply not have been enough time for them to mourn the loss of the "Joey of before" and come to terms with the "Joey of today." They do need to understand the potential suffering involved in future procedures and hospitalizations, and weigh that against their vision of his current and potential future quality of life. They also need an environment in which they can express their feelings about Joey openly and without being judged, by either the health care providers or each other! Parents in this situation often feel enormous guilt, about both the original event resulting in Joey's HIE ("If only I had gotten him out of the pool earlier" or "If only I had given better CPR..", etc.) and about the inevitable ambivalence about the state of his ongoing life. Most parents with a child like Joey have moments where they wish he were dead or had died in the hospital. These moments are frequently accompanied by enormous guilt. Joey's parents need to be able to express *any* feelings they have in a non-threatening and non-judgmental environment. One can help frequently just by letting Joey's parents know that others in their "shoes" have had the same feelings. In addition to allowing the parents to express their feelings, the nurses should be encouraged to express their concerns, also in a non-threatening environment.

Only after Joey's parents have been *fully* educated regarding his current condition and prognosis, *and* have been allowed to express their feelings in an open and non-judgmental environment, can we expect them to be Joey's best advocates as his surrogate decision makers. Once this occurs, the health care team needs to support them in whatever decisions they make regarding Joey's future. In addition, all

involved in Joey's care need to remember that his condition is not static, and decisions are not irrevocable. Interval meetings with Joey's parents, updating them on his condition and revisiting issues of ongoing care and status, should serve to continue the process of child advocacy in the case of this most unfortunate boy.

Robert Englander, MD  
Assistant Professor of Pediatrics  
University of Maryland School of  
Medicine

# CALENDAR OF EVENTS

## MARCH

- 23-28      The Center for Biomedical Ethics at the University of Virginia is presenting "Developing Hospital Ethics Programs," a unique six day course of study for healthcare professionals. This program offers CHE and CME hours. The course is designed to facilitate or strengthen the implementation of an ethics program within hospitals and other health care institutions. The DHEP program encourages discussion of the theoretical and practical aspects of a working program in patient care ethics and organizational ethics through a series of highly interactive sessions.

## APRIL

- 7      The Metropolitan Washington Bioethics Network will be presenting a program "Understanding the Definition of Brain Death," Howard University in the Towers. For more information contact Joan Lewis, Coordinator at (202) 682-1581
- 16      University of Maryland Medical System, Medical Humanities Hour: "Limiting Care in Managed Care Organizations: Towards Legitimacy and Fairness," by Norm Daniels, Ph.D, Professor of Medical Ethics, Department of Philosophy, Tufts University. 4:30-5:30 p.m., at the Shock Trauma Auditorium, University of Maryland Hospital, Baltimore, MD. For more information, call (410) 706-6250.
- 16      "Managed Care," a presentation by Dan English, M.D., M.A., of the Metropolitan Washington Bioethics Network will be held from 5:00-6:45 p.m. For more information contact Joan Lewis, Coordinator at (202) 682-1581.
- 17      James Frost Memorial Lectureship in Forensic Medicine and Ethics - 12:00 noon - 1:00 p.m. - Addition Auditorium, Robert C. Byrd Health Sciences Center, Morgantown, WV - "DNA Testing and Other Cutting Edge Technology in Criminalistic/Legal Medicine" - Henry C. Lee, MD, Director, State Police Forensic Science Laboratory Department of Public Safety State of Connecticut. For more information contact Cindy Jamison at (304) 293-7618.

## MAY

- 12      The Metropolitan Washington Bioethics Network will be presenting a program on the Task Force Report on "Standards for Bioethics Consultation." For more information contact Joan Lewis, Coordinator at (202) 682-1581.

- 14 University of Maryland Medical System, Medical Humanities Hour: "The Influence of Race on Health Care Decisions," by Taunya Banks, JD and Diane Hoffmann, JD, University of Maryland School of Law. 4:30-5:30 p.m., at the Shock Trauma Auditorium, University of Maryland Hospital, Baltimore, MD. For more information, call (410) 706-6250.
- 15 The 11th Annual WVNEC Symposium - "Working With Difficult Patients, Difficult Families, and Difficult Payors" - Main Auditorium - Robert C. Byrd Health Sciences Center, West Virginia University, Morgantown, WV - Topics to be discussed include abusive, noncompliant patients; demanding, unreasonable families; rationing by bureaucratic barriers; and other challenges in the everyday life of a late 20th Century Health Care Professional or Administrator. - Speakers: Donald C. Fidler, MD, Jacqueline J. Glover, PhD, Alvin H. Moss, MD, and Sandra A. Price, JD. For more information contact Cindy Jamison at (304) 293-7618.
- 21-22 "Families on the Frontier of Dying." A conference to hear from family members and loved ones who will speak about the life, struggle and death of someone dear to them. To be held at the Ritz Carlton Hotel, Philadelphia, PA. Co-Chairs are Arthur Caplan, Ph.D., Ronald Cranford, M.D., and Sally Nunn, R.N. For more information, contact Sally Nunn, RN at sjnunn@aol.com at the Center for Bioethics.
- 30 "Life and Death: Whose Decision is it Anyway?" Anne Arundel Hospital Conference Center, Annapolis, MD. Presented by the Maryland Healthcare Ethics Committee Network. For more information contact Anne O'Neil at (410) 547-8452.

## SUMMER

- June 18 The Shallenberger Lectureship presents: "Recognition and Management of Suffering" by Dr. Eric Cassell. To be held in Hurd Hall at the Johns Hopkins Hospital from 5:00-6:00 p.m.
- July 29 - August 1  
 WVNEC presents: "Developing Core Competencies in Ethics Consultation," a Summer Intensive Program in Clinical Ethics at the Canaan Valley Resort in Davis, WV. The Program will focus on the recommendations of the Joint Task Force of the Standards for Ethics Consultation and to introduce participants in these standards and assist them in developing the knowledge and skills to meet them. Program faculty include: Robert Arnold, MD, Co-Director of the Task Force, Jacqueline J. Glover, PhD, a Task Force Member, Alvin H. Moss, MD, and Sandra A. Price, JD. For more information or to reserve a space contact Cindy Jamison at (304) 293-7618.

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