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

January 1999 **99-1**

President's Message

Jim Wagner, Ph.D.
Patient and Family Resource Counselor
Shands at the University of Florida

The 1998 FBN Annual Conference in Orlando, "Current Challenges in Healthcare Ethics," was an excellent meeting. The attendance was lower this year, but the group size made possible broader participation in discussions. The location and dates for the 1999 meeting will be announced early in the new year.

As we begin our tenth year as an organization, there are a variety of issues we have identified as either continuing projects or new emphases. We want you to be aware of this agenda in the event you wish to participate or have input. The issues and contact persons for each are:

1. Continue to improve our educational efforts
   a. Newsletter content - Cathy Emmett
   b. Futility Policies - Jim Wagner
   c. Resource Manual for use in case consultation - Glenn Singer
   d. Website for FBN - Ben Mulvey

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In This Issue

Bioethics and the World-Wide Web

Ben Mulvey, Ph.D.
Associate Professor of Philosophy
Nova Southeastern University

For those interested in the ever-expanding field of biomedical ethics, the world-wide web affords another mode by which information can be gathered quickly. The web may well be a more convenient way for many to gather biomedical ethics information than traditional print journals for at least two reasons. First, much of the information there is offered at no cost to the user. Anyone with access to an internet-ready computer can use it. Second, the customizable search capabilities of much that is on the web can make searching for specific information relatively easy and quick.

At the recent annual FBN meeting I demonstrated some web sites that I have found particularly helpful. Since I have linked several biomedical ethics web sites to my own web site, I think that might be a useful place to begin. My web site can be found at www.polaris.nova.edu/~mulvey. Once there, scroll down the page to find the highlighted phrase "Biomedical Ethics." Clicking on that highlighted phrase will take you to my "Biomedical Ethics Page" where I have collected a number of links to other interesting web sites.

Space won't permit me to discuss each and every link listed on that page. But let me point out a few notable links. There are a number of links to educational sites administered by universities and ethics centers. For example, beginners to the field might want to click on the highlighted phrase "Bioethics for beginners" which will take them to the very well composed University of Pennsylvania's Center for Bioethics site (http://www.med.upenn.edu/bioethics/). Of course, as with most web sites, once you're there you click your way to a number of other sites.

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NETWORK NEWS

The newsletter of the Florida Bioethics Network

Network News welcomes letters, comments and articles for inclusion. Please send any correspondence to dmphotos@gte.net or Cathy Emmett, Hospice of Southwest Florida, 5955 Rand Blvd., Sarasota, FL 34238, Fax: 941-921-5813.

President's Message

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e. Managed Care Ethics - Katherine Koch

f. Elder Issues - Hana Osman

g. 1999 Annual Meeting format - Kathleen Weldon

2. Explore advocacy positions on several issues
   a. Reducing adverse events - Jim Wagner

   b. Standards for Concurrent Case Consultants - Ray Moseley

   c. Role of JCAHO in fostering a quality ethics process - FBN Board

3. Formalize efforts to strengthen FBN as an organization
   a. Membership growth & Institutional Membership - Michael Walker

   b. Pursue relationships with non-hospital providers - FBN Board

If you have an interest in any of these areas, please contact the appropriate person. At another place in this newsletter, numbers are listed.

The "Panel for the Study of Care at the End of Life," established by the Florida Legislature in 1998, is currently holding public hearings around the state. FBN is represented in this process directly or indirectly by Cathy Emmett, Jane Hendricks, Ken Goodman, and Ray Moseley. This process will develop recommendations for revisions to Chapter 765.

FBN is an organization rich with talent and characterized by a passionate membership. We want our strong voices to be heard on those issues where bioethics contributes. Renew your efforts to make your needs known and we will attempt to focus our resources constructively.

The entire FBN Board wishes you a peaceful and relaxing holiday season.

Bioethics and the World-Wide Web

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Specific organizations have informative web sites as well. For example, my web site includes a link to the *Hemlock Society* (http://www2.privatei.com/hemlock/), *Hospice* (http://www.safari.net/~hospice/), the *Health Council of South Florida* (http://www.med.miami.edu/HCSF/), the *American Society for Bioethics and Humanities* (http://www.asbh.org/), and the *American Medical Association* (http://www.ama-assn.org/).

Many important journals also have web sites as well, such as the *American Journal of Ethics and Medicine* (http://www.med.upenn.edu/~bioethic/ajem/index.htm), the *Journal of Medical Ethics* (http://www.jmedethics.com/), and the *New England Journal of Medicine* (http://www.nejm.org/content/index.asp) to name a few. Important documents like the oath of Hippocrates (gopher://ftp.std.com/00/obi/book/Hippocrates/Hippocratic.Oath) and the AMA's Code of Medical Ethics (http://www.ama-assn.org/ethic/pome.htm) can be found on the web as well.

The Philosophy of Guardianship

Submitted by Jane E. Hendricks, Attorney, Miami

Guardianship is the most intrusive legal intervention available, apart from civil commitment, and is probably the most widely utilized intervention.

Typically, society intervenes in the life of an individual who is found incapable of decision-making through the legal process of guardianship. Guardianship is a legally prescribed relationship in which the state gives one person (the guardian) the right and the duty to make decisions for, and act on behalf of, another person (the ward). Of the range of possible interventions, this is the most restrictive of the rights and privacy of an individual with diminished capacity. Depending on the extent of authority given to the guardian, the ward may be reduced to the legal status of a child, losing the right to control almost every aspect of life.

The consequences of guardianship upon the civil rights and liberties of the ward are many and drastic. The most significant right lost is probably the most basic civil liberty of all: the right of self-determination. This right to make choices about one's life and to determine where one's integrity as an individual. This ability to make choices is curtailed because guardianship proceedings result in the deprivation of a great number of civil liberties which most people take for granted. For example, the ward typically loses the right to manage his or her own finances, to write checks, to contract or sue

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Making Policy on Euthanasia and Assisted Suicide

A Comment on the Northeast Florida Bioethics Forum Position Statement

Ray Moseley, Ph.D.
Bioethics Advisory to the FBN
Director, Medical Ethics, Law and the Humanities
University of Florida College of Medicine

As I'm writing this Dr. Kovorkin is under indictment in Michigan for First degree murder for performing active euthanasia. I don't like Dr. Kovorkin! I don't like his cavalier attitude, his blatant in your face martyrdom. Frankly, I don't even like how he looks or the sound of his voice. He just doesn't look or act serious enough.

My reactions are not surprising, however since we know that discussions of euthanasia and assisted suicide evoke powerful religious, historical, political, emotional or even strong "self-evident" intuitive beliefs, both, in favor of, or opposing these practices. But how given these sorts of reactions should we in a pluralistic society formulate public policy on euthanasia and assisted suicide? More to the point, should bioethics organizations have a position on these subjects and if so on what should that position be based? First we should remember that Bioethics is all about critically analyzing and developing positions on crucial issues, in this case on euthanasia and assisted suicide. Simply put that means approaching an issue very carefully to make sure that we avoid precisely those personal biases and emotional responses that often unfortunately shape public perception. In other words one would hope that my personal feelings towards Dr. Kevorkin would not influence my deliberations on policy.

How do we avoid this problem in practice? There are several useful methodologies that bioethics offers. One that I often employ is a "shortcut" method of simply asking when faced with a reason either in support of, or opposed to euthanasia or assisted suicide whether that reason is a strong one or a weak one? Specifically, are the premises true? Is it logical (does the conclusion follow from the premises)? And are there good counter arguments, which are fairly presented? (Humans have a tricky tendency to present only the arguments that support the conclusions that want supported—this is called rationalizing!) For example we should not just appeal to those medical organizations, or religious or philosophical traditions which oppose assisted suicide to cite as authorities, as if other differing organizations or traditions did not exist. We also have to be very careful about the "facts" especially in how "facts" are often open to differing interpretations. For example, although the Hippocratic assertion against giving "no deadly drug..." is

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NORTHEAST FLORIDA BIOETHICS FORUM
POSITION STATEMENT:
PHYSICIAN-ASSISTED SUICIDE & EUTHANASIA

DEFINITIONS:

Physician-Assisted Suicide(PAS) - The physician provides a patient with the means and/or medical knowledge to commit suicide. The patient performs the life ending act.

Euthanasia - The physician administers the death causing drug or agent with the intent to end the patient's life.

Voluntary Euthanasia - Euthanasia performed on a competent person upon their request.

Non-voluntary Euthanasia - Euthanasia performed on an incompetent person upon the request of their surrogate.

Involuntary Euthanasia - Euthanasia performed on a patient without a competent person's consent.

Withdrawing or Withholding Life-Sustaining Treatment - Treatment that prolongs life, without necessarily reversing the underlying medical condition, is refused or removed after informed consent by the patient or surrogate allowing the patient to die of their underlying illness. This is not PAS or euthanasia.

Principle of Double Effect - Palliative treatment, with the intent to relieve suffering, that may hasten death.

POSITION STATEMENT:

It is fundamentally inconsistent with the historic ethical values and practice of Medicine for physicians intentionally to kill or to assist in killing patients. The Northeast Florida Bioethics Forum states its opposition to the practice or legalization of physician-assisted suicide or euthanasia in Florida.

THE PROBLEM:

Is it now ethical and defensible in Medicine that suffering of mind or body, infirmity, plague, or epidemic be 'treated' by killing until such time as our technology advances to prevent such suffering? To do so would be contrary to history, standard, and reason.

Support for physician-assisted suicide and euthanasia based on reasonings of increased compassion, patient autonomy, or stemming from patients who are inadequately palliated, or who fall outside Medicine's present ability to cure, is not sufficient to justify or offset the potential abuses inherent in these practices as stated:

I. The Relationship:

- Sanction will forever alter the tradition of Medicine and the public's perception of the profession as 'healers' whose sole purpose has been to safeguard the health and life of the patient.
- Public trust will erode as physicians and nurses are drawn inappropriately into decisions about "quality of life."
- Legalization increases undue involvement of third parties, particularly governmental and managed-care interests.
- Legalization may mandate terminally ill patients be offered physician-assisted suicide and euthanasia as treatment options in the informed consent process.

II. Patient Protection:

- Physician-assisted suicide and euthanasia, as the least costly option in the increasingly cost driven, managed-care environment, may be inappropriately weighted.
- Governmental sanction and Medicine's compliance may give the appearance of broad-based support for a 'duty to die' leaving vulnerable the poor, the infirm, the elderly or incompetent to subtle or overt pressures from family, physicians, or society and rendering their choice 'less free.'
- As proxy substitution is expanded for the physically and mentally afflicted, the very old, and the very young, euthanasia will become more widespread, less 'voluntary,' and the potential for abuse will increase.
- Patients with improperly managed physical symptoms or undiagnosed or untreated mental illness will be at risk.
- Assisted suicide and euthanasia may divert attention and funding from current terminal care approaches slowing research and advancements into end-of-life care.

III. Slippery Slope Concerns:

- Once **assisted suicide**, by competent patients, is sanctioned there is a strong argument for allowing **voluntary euthanasia**, by physicians, for competent but debilitated patients unable to self-terminate upon request. Once this is allowed, **non-voluntary euthanasia** for incompetent, debilitated patients unable to self-terminate will occur by "substituted judgment" and proxy request. Concerns that **involuntary euthanasia** of incompetent, debilitated patients without familial or proxy support, will then occur from a "best interests analysis," by both physicians and nurses, is warranted by the Dutch experience.
- Once sanctioned, physician-assisted suicide and euthanasia will be extended on demand to competent patients with non-terminal conditions who have intractable symptoms.

THE STANDARDS:

Formal Medicine must not condone or participate in assisted suicide or euthanasia. To do so would weaken a set of practices and restraints that could not easily be replaced. This approach to the ill and infirm is wrong by several standards:

1)**Traditional** - For 2500 years since Hippocrates physicians have vowed to, "give no deadly drug if asked for it, [nor] make a suggestion to this effect." Fundamental to our heritage is *'primum non nocere'* - first, do no harm.

2)**Professional** - The American Medical Association, the American Nursing Association, the American Osteopathic Association, and the Canadian Medical Association 'community' formally oppose assisted suicide and euthanasia.

3)**Historical** - The fact that suicide "has been illegal for centuries" was a pivotal and compelling argument in the 1997 unanimous United States Supreme Court decision overturning the Ninth Circuit Court of Appeals' "due process" argument for constitutionalization.

4)**Cultural** - "Physician-assisted death is opposed by almost every national medical association and prohibited by the law codes of almost all countries." (*Canadian Medical Association Journal* 1995; 152: 248A-248B)

5)**Legal** - Every state has local suicide 'prevention' laws. The Florida Supreme Court upheld the state ban in 1997 in *Krischer v. McIver*, ruling there was no right to assisted suicide under its 1980 right of privacy amendment. Federally, as noted, the Supreme Court has ruled against the constitutionality of physician-assisted suicide.

6)**Philosophical** - Opposition rests on "the paramount principle of the equal dignity and inherent worth of every human person." It holds to a prerequisite acknowledgement of the value of human life and cautions against the "unpardonable carelessness" inherent in the premise "that there is such a thing as a life not worthy to be lived." (Willke, JC, et al: *Assisted Suicide & Euthanasia - past & present*. Hayes Publishing Co., 1998, pp 13-14.)

7)**Theological** - "Most of the world's major religions oppose suicide in all forms and do not condone physician-assisted suicide even in cases of suffering or imminent death. In justification of their position, religions generally espouse common beliefs about the sanctity of human life, the appropriate interpretation of suffering and the subordination of individual autonomy to a belief in God's will or sovereignty." (Report 8 of the *American Medical Association* Council on Ethical and Judicial Affairs; Physician-Assisted Suicide: Appendix D: p.3)

THE RESPONSE:

The primary obligations of Medicine are: 1)to advocate for the dignity and autonomy of the individual patient, 2)to heal disease and injury through research and sound medical treatment at the bedside, 3)to preserve life, 4)to relieve suffering and 5)*'primum non nocere'* - attempt first to do no harm in the process.

Where the obligations to preserve life and to relieve suffering conflict, it is incumbent upon the profession, and our duty to the patient and to society, to provide the best care for the individual and to seek the moral high-ground of 'proper intent' for the whole. To these ends the Northeast Florida Bioethics Forum support the following actions:

1)To promote the idea of and movement from "curative care" to "comfort care" in terminally ill patients as the standard in the continuum of care.

2)To recognize and resist the natural tendency to withdraw physically and emotionally from terminally ill patients.

3)To respect and support the dignity and autonomy of patients to refuse life-sustaining treatments with the knowledge and assurance they will not be abandoned and will maintain access to our best efforts.

4)To demand aggressive and effective palliative treatment to control pain for all patients including:

a)To foster education of health care professionals about advanced pain management techniques, palliative care resources, and end-of-life issues.

b)To expect early consultation with palliative experts for those patients with refractory symptoms.

c)To support the formation of a coordinated referral system for access to palliative care here in Northeast Florida.

d)To support ongoing local research into more effective palliative treatments through calls for public, private, and governmental funding.

e)To support changes in laws and attitudes which limit access to adequate pain medicine for terminal care.

5)To promote a standard response by providers which triggers upon request for assisted suicide and euthanasia to assure that all medical, social, psychological, and spiritual circumstances are being or have been addressed.

6)To support the interdisciplinary approach for terminally ill patients and their families through the use of pastoral care, family counseling, specialty consultations for depression and active early hospice referral.

7)To specifically support our local hospice services, Baptist-St. Vincent Hospice, Hospice Northeast, and Methodist Hospice, through referrals and promotional support.

8)To foster patient independence through recommendations of Home Health Services and to promote family strength by supporting temporary lodging of patients through local Respite Care programs.

9)To educate the public about the inherent dangers of assisted suicide and euthanasia and to promote the current available services through public forums, lectures and promotional activity.

10)To challenge other institutions to stand together and oppose the promulgation and legalization of assisted suicide and euthanasia.

11)To provide expertise and support for legislative efforts opposing physician-assisted suicide and euthanasia in Florida.

12)To coordinate with state and national efforts through ongoing education, communication and speakers.

CONCLUSION:

The Northeast Florida Bioethics Forum stands in concert with Medicine's heritage in opposition to physician-assisted suicide and euthanasia.

For further information or comments, please contact:

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The Philosophy of Guardianship

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and be sued, to make gifts, and generally to engage in financial transactions of any kind. More importantly, the ward loses the very basic right of freedom of association and freedom of travel, as the guardian is usually given the power to determine the ward's place of residence and is thus empowered to place him or her in an institution of the guardian's choice.

Certainly, the loss of personal liberties and the stigma attached to the label "incapacitated" can be severe blows to the ward's sense of self-esteem. In light of the serious consequences of guardianship, it is important to understand the motivation behind its imposition.

The Basis for Intervention

The decision of the state to intervene in the private life of an individual rests upon the balancing of three different philosophical principles: (1) autonomy; (2) communal values; and (3) beneficence. The first, autonomy, is the foundation upon which our society and government are fashioned. In our society we believe, in general, that, except for causing injury to others, the individual should be given the utmost freedom to do as he pleases. Autonomy, however, is circumscribed by communal values and by the principle of beneficence.

The principle of beneficence, or paternalism, underlies state intervention where the state perceives that an individual's actions hurt, or threaten to hurt, him or herself. In that instance, the state restricts individual autonomy to act for the benefit and the good of the individual, not specifically for the protection of societal values.

Standing alone, each principle — autonomy, beneficence or communal values — is a noble goal. However, circumstances often bring the principles into conflict requiring that a choice be made between them.

In those instances where the individual's autonomy is threatened by communal values, it is important to step back and examine just what societal values are being threatened and the importance of those values when balanced against the individual's right to self-determination. Similarly, when an individual's decision is being overridden for beneficent reasons, the perceived danger to the individual and the good that might be accomplished by overriding that individual's autonomy must be carefully scrutinized and weighed against the dangers of limiting individual autonomy.

The Powers of the State to Intervene

There are two basic forms of power invoked by the state for the purpose of overriding autonomy and intervening in the private life of the individual. These two powers are closely related to the concepts of communal values and beneficence. When the state intervenes to protect itself and its citizens from the actions of an individual and its focus is on the interests of society, it intervenes under its police power. The criminal justice system is the most obvious example of the exercise of the state's police power. When state interventions are imposed for benevolent reasons (i.e. to protect the persons and property of those unable to care for themselves), the state acts under the doctrine of *parens patriae.*

The concept of *parens patriae* originated in England almost 700 years ago when the king was responsible for protecting and caring for the person and property of subjects who were mentally disabled. Literally translated, *parens patriae* means "the parent of the country."

The concept remains with us today. Under the *parens patriae* power, the state has the right and the imputed responsibility to step in and act in the best interests of those individuals who are unable to care for their own needs. It is the doctrine under which states assert the authority to appoint guardians as surrogate decision makers for incapacitated adults.

The paternalistic and benevolent purpose embodied in the *parens patriae* power has traditionally had a negative impact on the procedural safeguards accompanying its use. Despite the fact that the appointment of a guardian means the loss of important civil liberties, the procedural safeguards surrounding the imposition of guardianship have traditionally been very lax, and guardianship proceedings have customarily been regarded as informal and non-adversarial. Only in the past decade have there been significant efforts to reform state guardianship laws and practices.

Because of the asserted beneficial purpose of the hearing, many judges historically did not closely scrutinize the appropriateness of the intervention before granting the guardianship petition. Nor did the courts limit the scope of the guardian's power to that which was minimally necessary to protect the ward. The result was the imposition of plenary (absolute) guardianships when a lesser restrictive alternative such as a limited guardianship, or no guardianship at all, would have been more appropriate.

Contrast the traditional results under the paternalistic approach with the procedural safeguards imposed when the state's police power is invoked. The police power is the power retained by the states to insure the safety, health, morals and general well-being of its citizens. This power is invoked whenever an individual threatens that well-being. It is not invoked for the benefit of the individual, but rather for the benefit of the community. The police power is the power under which criminals are restrained and under which civil commitments traditionally were granted. Because use of the police power obviously pits the state against the individual, substituting the collective decision of the community for the values and decisions of the individual, the individual

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The Philosophy of Guardianship *continued from page 4*

is typically granted stringent procedural protections — i.e., the right to be tried by a jury of peers, the right to effective counsel, the right not to incriminate oneself, the right to meaningful notice, etc.

Despite the differing purposes of state intervention under its *parens patriae* and police powers, the consequences to the individual are substantial under both forms of intervention. Thus, while the laxity of guardianship procedural safeguards may seem justified by the beneficial purpose of the state's intervention, the state's motivation is largely irrelevant to the individual who suffers under its actions. For all too many wards guardianship is an inappropriate and overly restrictive intervention and is not beneficial. Not only is the ward deprived of a host of constitutional freedoms, but he is stigmatized by a determination of incompetence. The result is often resentment and alienation. Furthermore, there is evidence to suggest that the imposition of guardianship sometimes leads to involuntary confinement in an institution with a resultant hastening of death.

There is increasing awareness of the possibility of error inherent in any guardianship proceeding. In many jurisdictions, the laws have been revised and the procedural safeguards accompanying a guardianship petition are becoming more strict and more formalized. With this movement, the distinction between intervention under the state's police power and intervention under the state's *parens patriae* power is becoming less clear. Increasingly, it is recognized that individuals subject to guardianship, like those whom society attempts to control and punish through the criminal justice system, are at risk of losing important rights and are thus entitled to due process protection.

Save the Date

The University of Miami's seventh annual "Clinical Ethics: Debates, Decisions, Solutions" conference has been scheduled for March 26, 1999, in Fort Lauderdale. To be offered in conjunction with the Miami Area Geriatric Education Center, the conference will emphasize end-of-life issues, including advance directives. For more information or to receive a brochure when available, please contact:

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Making Policy on Euthanasia and Assisted Suicide *continued from page 3*

often interpreted as a prohibition against euthanasia, it is well to remember that most Hippocratic scholars interpretate this to be not about euthanasia, but to mean that physicians, with their knowledge of deadly drugs should not be involved with murder .... the everyday common type....political and for gain.

We must also avoid certain common philosophical fallacies. One fallacy that is quite common in discussions about euthanasia and assisted suicide is known by various names (i.e. Naturalistic fallacy, is-ought problem) but is basically the fallacy of appealing to a descriptively true situation as an argument in favor of what should be right. We often see this argument in appeals to authority. For example, the descriptively true fact that the AMA opposes euthanasia and physician assisted suicide does not mean in itself that euthanasia and assisted suicide are wrong. Just as neither does the fact that the Hemlock Society supports euthanasia mean that euthanasia is right. Those that would conclude this would have to do so on the hope or belief that the AMA has good reasons for their view, and not just on the fact that they are the AMA and they have asserted that view. Position statements must not only appeal to authority, but also and more importantly they must appeal to good reasons and reject opposing reasons. In the case of euthanasia and assisted suicide one must at least, address the powerful arguments which support these practices, namely that euthanasia and assisted suicide are appropriate examples of 1. The widely accepted right to self-determination, and 2. The utilitarian position that the greatest goodwill be achieved (given appropriate safeguards) by allowing euthanasia and assisted suicide.

I applaud the Northeast Florida Bioethics Forum for ambitiously taking on such an important and difficult topic. Also credit is certainly due for offering at least a partial positive response to the problems posed by euthanasia and assisted suicide. It should be noted at their statement on palliative care could be and in my view should be supported no matter what position one might take on euthanasia and assisted suicide.

Reader Comment Sought

What do you think? Do you support the statement proposed by the Northeast Florida Bioethics Forum? Why or why not? This group is very interested in hearing comments from around the state. Send your comments to Network News (dmphotos@gte.net or Cathy Emmett, Hospice of Southwest Florida, 5955 Rand Blvd., Sarasota, FL 34238, Fax: 941-921-5813). Please indicate on your response whether or not you are willing to have it published in the next issue.

Upcoming Conference

Ethics Committees: Developing, Participating in and Leading a Successful Hospital Ethics Committee, February 22-24, 1999, Radisson Hotel, Gainesville. Contact The Program in Medical Ethics, Law and the Humanities, University of Florida College of Medicine at 352-846-1097; Fax 352-392-7349 or e-mail moseley@chfm.health.ufl.edu

FBN Annual Meeting Date to Change!

After much discussion at the last two board meetings of FBN, we have decided to explore moving the conference to June, and are looking into hosting it in the Southeast Florida area. Details should be available in the next issue of *Network News*, but for now, pencil in the dates of June 10-13 or June 18-20 as possible meeting times. Kathleen Weldon is in charge of this next conference and will need assistance to plan a successful conference with such quick turnaround dates. Please contact her if you would like to assist and/or have suggestions for sessions and/or speakers.

Welcome New Members

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