

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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98-1

MESSAGE FROM THE PRESIDENT

Institutional Review Boards

The Florida Bioethics Network has emerged as a statewide resource for health professionals with an interest in bioethics. Since the network was created more than seven years ago, it has come to represent an educational and collaborative opportunity for nurses, physicians, social workers, clergy, lawyers, administrators, philosophers, and others. So far, however, the emphasis has been on clinical bioethics and the role and function of institutional ethics committees.

It is time to broaden our focus to include the state's many Institutional Review Boards, or IRBs.

Ethical issues in human subject research are among the most interesting -- and sometimes most difficult -- in all bioethics. The needs of IRB members and administrators for educational programs, counseling and consulting are every bit as great as those of ethics committee members. Yet, so far, there has been no concerted effort to meet that need.

In some respects, IRB educational needs are even greater than those of ethics committees. This is in part because many institutions handle comparatively few research protocols, and so have acquired less experience than would be optimal to provide adequate scrutiny of requests to approve experiments on humans. Let's put this another way: It's easy to get "ethically rusty" on a small or even mid-size IRB.

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NETWORK NEWS SURVEY

The Results Are In!

We asked for your response regarding Network News and we were gratified with your feedback. The majority of respondents agreed or strongly agreed with the statements that they read every issue, receive information that is useful and informative and that the style is clear and concise. A few of you felt that Network News could provide more current information and that the format could be improved. We heard that you read all or most of the Network News, and that you pass it along; in many cases to 6 or more people! There remains high interest in the topics of new problems and challenges in bioethics, changes in bioethics, pending legislation, trends and new developments, new regulations and case studies*. Interest was moderate (at best!) for FBN Activities and Editorials. Specific feedback on how to improve the Network News included suggestions of more articles from our members of all professions and an events calendar of upcoming educational offerings in the

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field of bioethics. Our thanks to all of you who took the time to respond. We will do our best to incorporate these comments and suggestions into upcoming issues of Network News. If you or your colleagues have interesting cases to submit, workshops, or articles of interest, please submit them to the editor as indicated on this page. We look forward to hearing from you throughout the year!

*One respondent suggested that this topic be deleted due to insufficient room for response.

NETWORK NEWS

*The newsletter of the
Florida Bioethics Network*

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Network News welcomes letters, comments and articles for inclusion. Please send any correspondence to cathy_emmett@smh.com or c/o Gerontology Dept., Sarasota Memorial Hospital, 1700 South Tamiami Tr., Sarasota, FL 34239.

Initiative With Department Of Elder Affairs

Ethical Concerns And The Older Adult

*Submitted by Hana Osman, LCSW, DCSW,
Education Team Leader, Tampa General Hospital*

In 1996, the State of Florida Department of Elder Affairs (DOEA) organized focus groups to begin to discuss the ethical issues facing older adults and their families. Later, in May 1997, the DOEA and the Florida Council on Aging (FCOA) spearheaded an ethics initiative and formed an Ethics Think Tank. This Think Tank included representatives from the DOEA, the FCOA, the Florida Association of Service Providers, the Florida Health Care Association, the Florida Nurses Association and representatives from many other organizations interested in the older adult. A representative from the Florida Bioethics Network (FBN) was also invited to participate in the discussions about the ethical concerns that arise in the daily activities of staff members working with the elderly population.

There are similarities between the concerns of the FBN and those of the newly formed group under the leadership of June Noel, Deputy Secretary of the Department of Elder Affairs. Some of those concerns relate to impaired decision making, advance directives and end of life decisions. Subsequent to the initial Ethics Think Tank meeting, two training sessions were offered by Ray Moseley, Ph.D. and Bill Allen, J.D. to the interested parties.

Resulting from the focus groups, the Think Tank discussions and the training sessions, a field guide was published for the use of community agencies interested in the ethics initiative. In 1997, the guide entitled: *Coming of Age... Sharing Responsibility, A Field Guide for Community Initiatives on the Ethics and Responsibility of Aging* was published by the State of Florida Department of Elder Affairs. The Guide was prepared in consultation with the Department of Elder Affairs by Margaret Lynn Duggar & Associates.

The DOEA, the FCOA and the FBN are considering ways of cooperation and collaboration to meet the needs of the community. In the October FBN Board meeting, June Noel addressed the Board to present the ethics initiative. The Board agreed that the FBN shares the interests of the DOEA and the FCOA and will continue to search for means of collaboration in the form of joint educational activities and in other ways to be identified as the mutual objectives crystallize and the relationship matures.

A Book Review of Dying Well: The Prospect For Growth At The End Of Life by Ira Byock, M.D.

Submitted by Rev. Jerry Griffin, BCC System Program Director, Spiritual Services, Lee Memorial Health System

One might wonder why a book by a hospice doctor (medical director) would be reviewed in the FBN Network News. Actually, when we think about it, there are several good reasons. And, they are scrolled into the script of this book of challenges to the "traditional ways."

Ira Byock, M.D. is the President of the American Academy of Hospice and Palliative Medicine. He has appeared on many significant talk shows, in documentaries on pain management and the quality of life and in speaking engagements across the United States. His presence in the arena of discussion on the PBS presentation, "Before I Die," is an in-person testimony to the concepts offered on the pages of this call for quality of life.

In my words, there are some subliminal messages recurring in the scenarios in DYING WELL. The obvious qualities of "benemortasia" are characterized openly and frankly in the lives and efforts of the casts in the stories of living until death. The recurrent themes which began to tug at my consciousness after five or six of the personal accounts are the ones which confront the ethics and morality of life on the pathways of the terminal pilgrimages.

Pain, abandonment, isolation, imposition of styles for dying, spiritual emerging and reinforcement of individual rights are the issues expressed over and over. The personages of the Missoula area are met with the dynamics of Dr. Byock's own quest for fullness of life during the last days of his father's life. Perhaps, this is the greatest unwritten quality of this book: a physician's transparency and passion about his desire for people to live while dying.

The desolation of the climate and terrain of Montana are nothing compared to the forces encountered by the people who are the main characters in the ten Missoula Hospice clients and their families herein depicted. Anne-Marie, Steve, Michael and Maureen are four of them. Their struggles urge the reader to do all within the power and resources available to translate the suffering of our patients and families into growth and enrichment. Heaven forbid that our folks would have to endure as those people did!

The final chapters, "Getting There From Here: Social and Cultural Dimensions" and "Writing Your Family's Story: Questions and Answers," reward the reader with some of the keys to growth at the end of life. Dr. Byock's passion for the pursuit of diminishing the occurrence of death before death through inter-personal and psychological "deaths" emerge in full "color" in these pages. The stories become clinical examples of the need for the adoption of the transparent communication styles into our own lives and practices. Our own rigidities and securities in the "traditional" are blocks to guiding our clients to experience growth at a time when wilting is often considered the vogue.

I urge you to read this book. It is a challenge to each of us to do more than get in touch with the mind, body and soul. It is a call for us to meet the moral mandate that persons be given the ticket to full expressions of their persons at a time when many practitioners encourage "shut-down."

One reviewer of the book wrote, "If you or anyone in your family fears dying in pain, considers dying only a series of losses, or thinks a dying person is a burden, read this book! In it there are instances of personal development and deepened spiritual peace in people who are dying, of increased closeness in families and of the healing of troubled relationships."

Read it! You'll be challenged to live it so that others can live...until death.

Case Study

Many of our regular readers are familiar with our past format of presenting a bioethics case with a commentary from one of our members or another healthcare professional in the field. We would like to try something a little different for the next several issues. We will present the case study as before, but for the commentary we are looking to you our readers! Please submit your commentary to the Network News Editor as indicated at the end of this case study and we will publish the responses in the next issue. The following case study was submitted by Kathryn Koch, M.D.

The Case of Mr. B

Mr. B is a 63 year old electrician. Over the past few years he has had a general decline in vigor, and has been taking the easier jobs as well as more sick days. Hypertensive for ten years, he has never been under good control. A one to two pack a day smoker since the age of 13, he drinks moderately and uses no drugs other than those prescribed.

Mr. B is admitted to the hospital for evaluation of heme positive stool, a fall in hemoglobin from 15 to 10 over a three month period, increasing shortness of breath with exercise, new onset of anginal chest pain with exertion, and a rise in BUN and Creatinine from 10 and 1.0 to 30 and 2.0 respectively.

An acute myocardial infarction is ruled out. An echocardiogram reveals hypertensive cardiomyopathy with decreased shortening fraction but no segmental wall motion abnormality. Cardiac cath reveals diffuse but non-critical coronary artery disease. It is elected to proceed with his GI tract workup as his still remains heme positive and his hemoglobin continues to drop. During colonoscopy he becomes acutely short of breath and hypoxic, requiring abortion of the procedure. He receives intubation and emergency transfer to the intensive care unit.

Mr. B is found to be in acute pulmonary edema with renal failure on top of chronic obstructive pulmonary disease with hypoventilation, in addition to his other problems. He receives emergency dialysis which turns into chronic dialysis. He develops aspiration pneumonia which requires 4 weeks and a tracheostomy to wean him from ventilator support. During this time he repeatedly expresses his wish to receive any necessary interventions to optimize his recovery and sustain his life. He undergoes repeat colonoscopy, and a polyp with moderate carcinomatous degeneration is removed.

At this point he remains severely debilitated, despite bedside physical therapy for the previous three weeks of his ICU stay. He is able to get out of bed with assistance, but cannot ambulate. It is recommended that he be transferred to a subacute care hospital, where he can receive rehabilitative physical therapy, airway management, and ongoing hemodialysis. His managed care contract has no provisions for this level of care.

He is transferred to the regular med-surg floor. His physicians there encourage a DNR decision, and his wife and 3 children concur. He does not agree. He makes it for 3 days before he develops an increase in sputum production and a near respiratory arrest from inadequate suctioning. He is returned to the ICU with a new pneumonia.

The issue of level of care is again addressed by the ICU physicians; he continues to desire full resuscitation. His wife and children do not visit. The case manager for the managed care contract inquires about his code status, and is informed that he has repeatedly requested "full code." He recovers after 2 weeks to the point where he no longer requires ICU level care, and is returned to the med-surg floor.

During the week he spends on the med-surg floor, the case manager from his managed care contract has a meeting with his family and floor physicians regarding his code status. They are all in agreement that he should be a "no code." Before this is again addressed with him, he develops another complication from inadequate suctioning and requires a return to the ICU.

The case manager for the managed care contract demands that his ICU physicians discuss his code status with him, and that she be present during the discussion.

FBN Members turn to respond—How would your committee respond if asked to consult on this case? What questions would you ask? What persons would you want to talk to? Please send your comments to cathy-emmett@smh.com or mail to 1700 South Tamiami Tr., Gerontology Dept., Sarasota, FL 34239.

The South Florida Medical Futility Project: Current and Future Direction

Submitted by Lisa L. Noke, Project Director Health Council of South Florida, Inc.

Over the past three years, the Health Council of South Florida has engaged in a study of Medical Futility and the community of South Florida's response. During the fourth quarter of 1997, The Health Care Ethics Committee of the Health Council of South Florida disseminated conclusions from community forums held over the summer. The community forums focused on end-of-life issues and targeted audiences such as: health professionals, elders, adolescents, religious leaders of all faiths and denominations, and persons living with HIV/AIDS. Though the forums were aimed at dissimilar community populations, perspectives and conclusions concerning end-of-life decision making were comparable. These conclusions were not only presented at the 7th Annual Florida Bioethics Network Conference in Tampa, Florida in October, but at The Joint Meeting of the American Association of Bioethics, Society for Bioethics Consultation and Society for Health and Human Values in Baltimore, Maryland in November.

In Baltimore, participants from selected cities conducting or seeking to pursue similar efforts attended the presentation. The breakout session elicited suggestions to be incorporated into the document. More emphasis on the hospital/physician relationship instituted into the guidelines was deemed appropriate to address a broader scope of issues. Secondly, the need to discuss the composition

of institutional review systems and ethics committees was identified as a necessity in the guidance of "medically futile" cases. The Health Care Ethics Committee members are now reviewing feedback from both presentations. This course will result in further revision of the draft guidelines.

Future direction of the South Florida Medical Futility Project will include publication of the findings on a statewide and national level to foster development of guidelines in other geographic areas. An analysis of other geographic regions involved in medical futility studies will be executed, to compare and contrast the accomplishments of the South Florida Medical Futility Project. Because the need for community education was clearly indicated, the Health Council plans outreach to health care institutions and community groups not previously involved with the project. Through public educational symposiums, the Health Council will promulgate further dialogue and seek development and implementation of community strategies and institutionally based policies.

The Health Care Ethics Committee is seeking all points of view. The draft guidelines can be found on the Health Council's web site at www.med.miami.edu/HCSF/, along with a feedback form for comments. For additional information, please contact Lisa Noke at The Health Council of South Florida, Inc. at (305) 263-9020.

FMA Journal Sponsored by FBN Members

FBN Board members Kathym Koch, M.D. and Glenn Singer, M.D. are the guest editors of the November issue of the Florida Medical Association Journal on Bioethics: Communicating With Our Patients. Dr. Singer discusses disconnection of the Ventilator while Dr. Koch's article focuses on The Ethics of Managed Care. Other FBN Board Members writing for this special issue include Ben Mulvey, PhD, Ken Goodman, PhD and James Wagner, PhD addressing the issues of Guidelines for Ethics Committees, Electronic Health Data and Adverse Outcomes. If you do not receive this journal, check with your medical library or physicians that you work with. FBN will try and get a copy out to each of our members. Our thanks to Glenn and Kathryn for all their hard work in putting this special issue together and congratulations for a job well done!

Position Available

Full, Associate, or Assistant Professor Center for Bioethics, University of Minnesota

The University of Minnesota invites applications for a faculty position in the Center for Bioethics and the University of Minnesota Medical School. This position is a tenure/tenure track position at the Full, Associate, or Assistant Professor level. The appointment will be 50% in the Center for Bioethics and 50% in the relevant medical school department, with commensurate clinical care responsibilities. Salary and rank commensurate with experience.

The person in this position will be expected to join in the Center's educational, research and service activities, particularly in the area of the ethical issues involved in the delivery of clinical care. The successful applicant will be an academic physician with a track record of research in bioethics. Applications received prior to April 15, 1998 will be assured full consideration, though applications will be considered until the position is filled.

Start date on or after July 1, 1998. Send a letter of application, CV, and names of three references to: Search Committee, Center for Bioethics, N504 Boynton, 410 Church Street NE, Minneapolis, MN 55455-0346. For more information, contact: Dianne Bartels, Associate Director, Center for Bioethics, N504 Boynton, 410 Church Street SE, Minneapolis, MN 55455-0346. Telephone 612-624-9940; Fax 612-624-9108; E-mail barte001@tc.umn.edu. *The University of Minnesota is an equal opportunity educator and employer.

IRBs (continued from pg. 1)

Even the busier IRBs have lacked the kind of educational opportunities that ethics committee counterparts enjoy. In an effort to address this, the Florida Bioethics Network at its Annual Meeting in Tampa in October included a session on ethical issues in public health research with presenters from the Florida Department of Health IRB. But there is much more that needs to be done. Here is a brief list of some of the questions and issues that Florida's IRBs need to be familiar with:

- Criteria for valid or informed consent
- Consent form readability
- How to weigh risks and benefits to subjects

- Protections for vulnerable populations (including children, mentally impaired patients, and some elders)
- Laws and guidelines (including the Code of Federal Regulations, Food and Drug Administration and Office of Protection from Research Risks guidelines and Florida Statutes)
- Investigator conflicts of interest

Of course, there are many other issues that a competent IRB needs to be able to address. The goal of this column is to spark interest in bringing IRBs into the Florida bioethics fold. To that end, it will be a good idea if IRBs can begin to benefit from some of the networking opportunities that others have enjoyed through the FBN. Let's begin by compiling a list of interested IRB chairs and member.

If you are interested in learning more about -- and perhaps even helping to develop -- educational opportunities for IRBs, please let us know by writing to the FBN at Box 531107, Orlando, FL 32853-1107, fax: 407-423-4648; or to me at the Forum for Bioethics and Philosophy, University of Miami, PO Box 016960 (M-825), Miami, FL 33101, fax: 305-243-3328, E-mail: ethics@newssun.med.miami.edu.

On a related note, interested IRB members should save the dates of April 27-28, 1998, when the U.S. Office of Protection from Research Risks (OPRR) and the University of Miami Office of Research Standards will sponsor a special IRB conference in Miami titled "The Interface of Science, Ethics and Law in Human Subjects Research." Please let us know your address to receive further information about this program.

* * *

This is my first column as FBN president. I am excited and honored to have the opportunity to work with members and with other officers to foster the continued growth and productivity of this organization. A special acknowledgment is due my predecessor: Glenn R. Singer, M.D., chair of the Department of Pulmonary Medicine at Broward General Medical Center in Fort Lauderdale. Glenn did an outstanding job as president of the organization, which is stronger and larger than when he assumed the post. FBN members and, indeed, all with an interest in bioethics in Florida, owe him a debt of gratitude for his service, his organizational skills and his wise counsel.

*Kenneth W. Goodman, Ph.D.
FBN President*

Upcoming Conferences

Ethics Committees: Developing, Participating in and Leading Successful Hospital Ethics Committee, Feb. 16-17, 1998, University Centre Hotel, Gainesville, FL, University of Florida, 352-392-4321.

Future of Dying, April 24, 1998, University of South Florida, Sarasota Campus, Sarasota, FL, Sarasota Memorial Hospital, 941-917-1750.

Clinical Ethics Conference

The University of Miami Forum for Bioethics and Philosophy has scheduled its sixth annual conference, "Clinical Ethics: Debates, Decisions, Solutions," for February 20, 1998, in Hollywood, Florida.

The conference, which traditionally offers continuing education credits for a variety of health professionals, will feature the following speakers:

- Baruch A. Brody, Ph.D., Director of the Center for Medical Ethics and Health Policy at Baylor College of Medicine: "The Truth, The Whole Truth, and Nothing but the Truth: Challenges in Giving Bad News to Cancer Patients."
- Laurie Lyckholm, RN, MD, Medical College of Virginia: "Genetic Testing for Breast Cancer Susceptibility: Catching up to Science."
- William Nelson, Ph.D., Department of Veterans Affairs' National Center for Clinical Ethics: "Use of Ethics Advisory Committees for Oncology-Related Conflicts."

The conference will also include special sessions on ethics and hospital administration, health law and ethics, pastoral care, phase I clinical trials, ethics and psychology, and the problem of false hope for gravely ill people. Small group sessions are also planned.

For more information, to receive a brochure, or to register, call the University of Miami Division of Continuing Medical Education at 305-243-6716; fax: 305-243-5613; or send E-mail to ethics@newssun.med.miami.edu.