Florida Bioethics Network FBN

Florida Bioethics

Autumn 2002 http://www.med.ufl.edu/chfm/ethics/fbn/ Email — ethics@miami.edu

'Such Ugliness' — Schiavo Case Enters New Phase As Courts Try to Sort Out Family Dispute, Allegations

CHANTAL ABITBOL
Special to Florida Bioethics

Terri Schiavo's feeding tube may not be removed until an appellate court hears more evidence in the case, the court has ruled. Oral arguments were scheduled for April 4.

Circuit Judge George W. Greer had earlier ordered that Ms. Schiavo's life support be discontinued on Jan. 3. He then stayed that ruling, and, on Dec. 23, the 2nd District Court of Appeal agreed, in essence giving Ms. Schiavo's parents more time to halt her husband's efforts to terminate life support.

It means that a new chapter is beginning in the legal life-and-death tug of war.

Twelve years ago, Ms. Schiavo, 38, suffered a heart attack that cut off oxygen to her brain, condemning her to a coma-like state. Since 1998, her husband, Michael Schiavo, has asked the court's permission to disconnect his wife's life support. He argues she is in a persistent vegetative state and beyond help.

On the other side are her parents, Bob and Mary Schindler, who say their daughter reacts to them and could be rehabilitated with new and aggressive therapy. They want to replace Mr. Schiavo as guardian so they can assume control over her care.

In November, Judge Greer, who first heard the case two years ago, sided with Mr. Schiavo more than a month after the conclu-

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In this issue

FBN Meetings, Projects Continue to Serve, Educate

The Florida Bioethics Network has continued to expand efforts to provide educational programs around the state – in one case joining with a hospital and the Florida Partnership for End-of-Life Care to earn a proclamation establishing "living will day," and, in another, laying plans for a major bioethics conference in the state capital.

Spurred by Arthur Berger, a prominent South Florida attorney and member of the Aventura City Council, a regional consortium of health care and allied entities joined forces to distribute hundreds of living wills – and to provide free advice about advance directives.

Aventura Hospital and Medical Center hosted the "living will day" and treated hundreds of attendees to breakfast and a series of talks and guidance sessions. The list of partners and co-sponsors was impressive:

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Florida Bioethics Network

The Florida Bioethics Network is a program of

- **Program in Bioethics, Law, and Medical Professionalism, University of Florida College of Medicine**
- **Bioethics Program, University of Miami**
- **Division of Medical Ethics and Humanities, University of South Florida School of Medicine**
- **Nova Southeastern University**

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Florida Bioethics
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The Web site is hosted by the University of Florida Program in Bioethics, Law, and Medical Professionalism: fbn@chfm.health.ufl.edu

Florida Ethics Calendar

Please e-mail submissions to ethics@miami.edu

January 10, 2003, Tallahassee — **Florida Bioethics Network** northern region conference. "Bioethics in the Capital" will feature keynote presentation by Harry Lee Anstead, Chief Justice of Florida's Supreme Court, end-of-life updates, "Ethics in Florida," child advocacy, and more. 850-656-8848, 305-243-5723 or the FBN Web site.

January 17-18, 2003, Davie — "A Glimpse of the Future of Health Care in America," a 2-day program sponsored by Nova Southeastern University's Health Professions Division. Speakers include Sen. Jim King, President of the Florida Senate, Yank Coble, M.D., President of the American Medical Association, and Mary E. Alexander, M.P.H., J.D., President of the American Trial Lawyers Association. 954-262-1597, 954-262-1501, or 800-356-0026).

January 17, 2003, Miami Beach — "Masters of Pediatrics" session on HIPAA and pediatrics, University of Miami School of Medicine, 305-243-3922, 800-622-4453.

February 27, 2003, Key Biscayne — "Oceans and Human Health: Risks and Remedies from the Sea," town meeting to include component on environmental health and ethics. Sponsors: National Institute for Environmental Health Sciences, University of Miami Marine and Freshwater Biomedical Sciences Center, Florida International University and others. 305-361-4748/-4736, gforteza@rsmas.miami.edu.

March 7, 2003, Fort Lauderdale/Hollywood — Clinical Ethics: Debates, Decisions, Solutions (**Florida Bioethics Network** spring conference and University of Miami 11th annual conference). Focus sessions to include a HIPAA track, aging and dementia, ethics committees. 305-243-5723, ethics@miami.edu

October 16-19, 2003, Clearwater Beach — FEAST — the Association for Feminist Ethics And Social Theory — will hold its 2003 conference. For more information or to see the program from the 2001 conference, go to http://www.afeast.org.

Baptist Health Systems Names Full-time Ethics Coordinator

Special to Florida Bioethics

Rose Allen

MIAMI – Rose Allen, an ICU nurse, has been appointed to the newly created position of Bioethics and Patient Rights Coordinator for Baptist Health Systems, a four-hospital network in south Miami-Dade County.

The creation of the full-time position is apparently the first of its kind in the state.

The appointment was made by Tim Hawkins, Vice President of Clinical Services at Baptist Hospital.

"This is a big step towards creating an ethics culture that will involve all the hospitals of the system," said Raul de Velasco, M.D., chair of Baptist's system-wide Ethics Committee. He said Allen's responsibilities will include the coordination and standardization of the systems' ethics policies and education programs. Beside Baptist, the system includes South Miami, Homestead and Mariners' hospitals.

A native Jamaican, Allen migrated to England at age 17 to pursue a nursing career. After obtaining a diploma in nursing, she relocated to the United States to marry. Her career in the United States started out in a coronary care unit and led to a critical care certification, a bachelor of science in nursing, and a master of science in management with specialization in healthcare management.

Allen has taken over coordination of the system's ethics consultation process, a number of educational activities and coordination of a popular monthly series of "Conversations in Ethics" in which clinicians, community leaders, academics and others lead open forums on various issues.

Broward Judge Orders Doctors to Provide Unproven Treatment

JOSE DANTE PARRA HERRERA
South Florida Sun-Sentinel

FORT LAUDERDALE — He was 20 months old and an only son, but doctors asked his family to consider disconnecting him from life support and letting him die.

With their backs against the wall, Dr. Jeffrey Weiss and his wife, Judith, searched for another option. They found a treatment in which their son could breathe pure oxygen, in hopes of jump-starting the toddler's brain cells. A long shot, but a chance nevertheless.

The Weisses told doctors at Broward General Medical Center, where Justin lie dormant in intensive care, that an expert was willing to bring his equipment to the hospital to treat the child.

But the hospital said no. The technology has never been tested on children and pure oxygen could pose a fire hazard, hospital staffers said.

As time ticked away, the Weisses asked a judge to force the hospital to allow an outside specialist to treat Justin. In an emergency hearing, their wishes were answered.

"The doctors [at Broward General] have nothing to offer my son to help him," Weiss said in a high-pitched, cracking voice. "How much more can you hurt him if you want me to kill him?"

Circuit Court Judge John A. Miller said he did not see any reason why Justin should not be given another option, provided Justin's parents were willing to free the hospital from any liability arising from the treatment.

But attorney Reid A. Cocalis, who represented Broward General at the hearing, said that the treatment was fringe medicine at best, and challenged advocates to produce any studies on the effects of the treatment on children.

In the end, the child was taken home and the experimental treatment was rendered there.

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ETHICS BRIEFS:

ON-LINE COURSE ON END-OF-LIFE CARE

A new web resource, Finding Our Way: Living with Dying in America — The Online Course (www.scu.edu/fow), is available. The free course is part of the Finding Our Way national public education initiative focused on bringing practical information on end-of-life issues to the American public. The course is completely self-paced and all course materials are included on the web. This online course grew out of a 15-part national newspaper series distributed by Knight Ridder/Tribune that appeared in more than 160 newspapers,

WEB SITE PROVIDES HIPAA EDUCATION

Health care workers going nuts over HIPAA compliance may find help in a new and comprehensive Web site. Created by the University of Miami Ethics Programs, the site — http://privacy.med.miami.edu — provides tutorials, a glossary, links to key resources and other tips and tools. HIPAA compliance requires education in individual policies, so the site needs local augmentation. Faculty are available for developing institution-specific training efforts. More information: 305-243-5723.

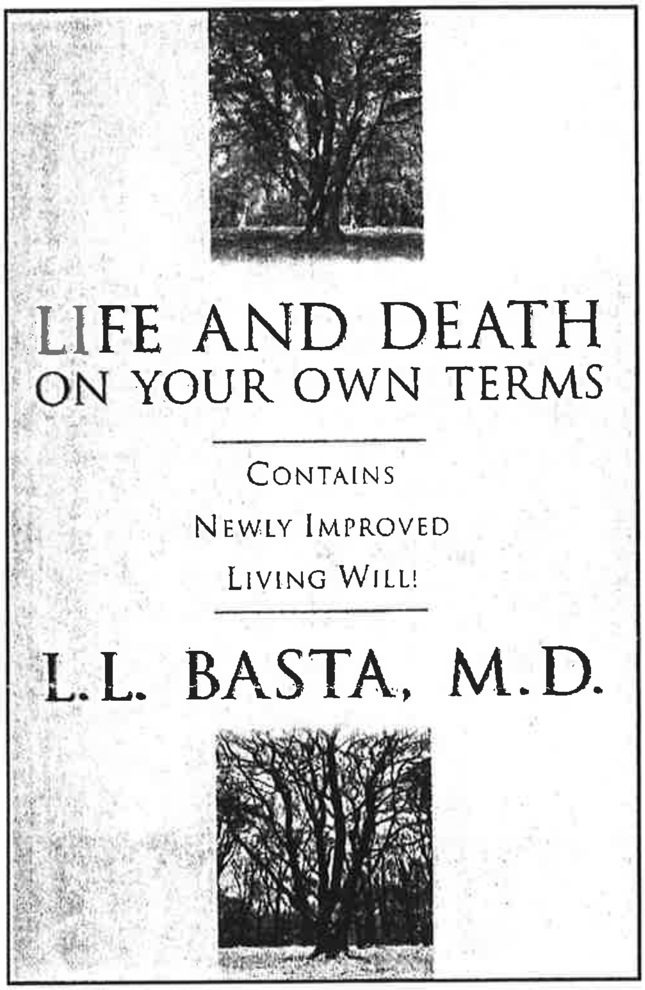
FBN BOARD MEMBER CO-EDITS NEW VOLUME

Robin N. Fiore, Ph.D., an FBN board member and Florida Atlantic University faculty member, and Hilde Lindemann Nelson, Ph.D., who gave a keynote talk at the FBN's 2001 conference in Fort Lauderdale, have edited *Recognition, Responsibility and Rights: Feminist Ethics and Social Theory*, a new book from Rowman & Littlefield. This collection of essays by prominent feminist thinkers includes pieces on anorexia, dementia, disability, transgender and euthanasia. Order it at http://www.rowmanlittlefield.com/.

Project GRACE

Planning for End-of-Life Care — A Prescription for Progress

LOFTY L. BASTA, M.D., FACC
Founder of Project GRACE



LIFE AND DEATH
ON YOUR OWN TERMS

CONTAINS
NEWLY IMPROVED
LIVING WILL!

L.L. BASTA, M.D.

TAMPA — The events of September 11, 2001, resulted in the brutal awakening to the unalterable truth: life is fleeting, precious, irretrievable, unpredictable, and tenuous. Now, with the advent of another new year, many Americans are reassessing end-of-life planning. This includes financial and medical treatment planning.

The "Living Will" and "Advance Directives" are generally regarded as adequate instruments to guide medical treatment near the end of life. Unfortunately, they fail to fulfill their promise in the majority of cases. But why? A little bit of history is useful to answer this question.

The Living Will concept was first proposed in 1969 by Luis Kutner during a meeting of The Euthanasia Society of America. Mr. Kutner proposed the Living Will as a document to express the sentiment of many that when death is near and unavoidable, dignity and comfort should take precedence over feats to prolong life and postpone the moment of death when there is no promise to add quality to the last days of life.

The first proposed Living Will was worded in sentimental language that resonated with many citizens: "... death is as much a reality as birth, growth, maturity, and old age – it is the only certainty in life. If the time comes when I, ___, can no longer take part in decisions for my own future, let this statement stand as an expression of my wishes, while I am still of sound mind. If the situation should arise in which there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial means or 'heroic measures.' I do not fear death itself, as much as the indignities of deterioration, dependence, and hopeless pain. I, therefore, ask that medication be mercifully administered to me to alleviate suffering, even though this may hasten the moment of death."

This pioneering "will" has the virtues of brevity and simplicity. Clearly, the person executing the will knew what he or she wanted. "I wish to be spared the pain, indignity and cost of unnecessary medical interventions at the end of life. I long for a graceful exit."

Unfortunately, the intent, spirit and promise of this "will" was virtually lost in the feud between doctors, lawyers, ethicists, theologians, families, and society. Doctors view it as too ambiguous and non-specific; lawyers have difficulty seeing how the document could be legally binding; ethicists analyzed it, criticized and ostracized it; and families ignored it.

The shortcomings of such a "will" can be illustrated best by the case of Mr. Jones (true story, fictitious name). At age eighty-four, Mr. Jones lost his wife of 62 years, after an arduous battle with cancer and complications requiring placing Mr. Jones on life support for several weeks. After Mrs. Jones' death, Mrs. Jones executed the above-quoted living will and summoned his three daughters, saying "... I had my life. Each of you has her life with your husband and children. I do not want for you to worry about me." He went on to explain, "After your mother's death, there is no joy left for me. I long for dying, in order to be with your mother. You have to mind your own business and forget about me..."

Mr. Jones stopped taking his blood pressure medicine and developed a massive stroke that rendered him totally paralyzed on the right side, wheelchair bound; he lost

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"Making Choices" Collection is a Partnership Milestone

TALLAHASSEE – In one of the broadest town-gown collaborations in state history, the Florida Partnership for End-of-Life Care has completed work under a three-year grant from the Robert Wood Johnson Foundation. Deliverables:

- Statewide training and curricula on end-of-life care
- Creation of community coalitions
- Establishment of alliances and working relationships
- "Making Choices" – a 69-page booklet with articles on topics ranging from DNRs and emergency medical services to hospice and pain management.

Indeed, it is arguable that Florida law is better as well: the Partnership had among its goals the improvement of laws governing advance directives.

The Partnership, in addition to creating a statewide network of community coalitions that worked – and continue to work – on a broad array of service projects, also linked Florida's Hospice and Palliative Care group, the state Department of Elder Affairs, ethics programs at the University of Florida and the University of Miami and an ensemble of state leaders, educators and others.

That is reflected in the "Making Choices" booklet, which features articles designed to be accessible to a broad audience. The document includes important messages on death and dying from Gov. Bush and Elder Affairs Secretary Terry White.

The FBN was a key partner in the effort. All FBN members have or will receive a courtesy copy of the document; a limited number of extra copies are available. Additionally, the booklet is being translated into Spanish; this version will be available shortly.

FLORIDA PARTNERSHIP for End of Life Care

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his ability to express himself and had difficulty swallowing.

Because of these problems, Mr. Jones suffered attacks of aspiration pneumonia (lung infection resulting from food going into the air pipes). With each episode of pneumonia, Mr. Jones was rushed to the hospital and often was placed on the ventilator. This recurred many times. Presently, Mr. Jones is 96 years old, confined to a wheelchair for 12 years, kept alive in a state that he clearly resented and would have characterized as void of fun and dignity. What went wrong?

The main reason for this unfortunate outcome is the vagueness of language of the advance directive. Such terminology as "terminal illness, irreversible disease, heroic measures, and artificial means" is subject to various interpretations. A stroke, even crippling, cannot be characterized as a terminal illness. The application of a ventilator to assist in the treatment of a potentially curable pneumonia can hardly be considered as "heroic" and the term "artificial means" is already too vague and could apply to any medical intervention, since most medical procedures in one way or another utilize "artificial" means.

Advance directives are supposed to provide "clear and convincing evidence" of a patient's wishes. They do not achieve their goal when their language is unclear and unconvincing.

Project GRACE underscores the importance of proper advance care planning using medical scenario-specific language. The foundation's Advance Care Plan (ACP) document has the virtues of simplicity, brevity, clarity, and specificity. It is written in plain English and covers most end-of-life medical scenarios, including permanent unconscious state; total confusion from irreversible brain disorder; terminal stages of cancer, heart failure, lung disease, and untreatable infections such as AIDS; as well as conditions of advanced senility with decrepitude and total dependence upon others to carry out all daily functions such as feeding, bodily hygiene, mobility, etc. With each of these medical scenarios, the patient is asked to choose among various treatment options, including cardiopulmonary resuscitation (CPR), life support, treatment of a complicating condition, such as pneumonia, and artificial feeding. This document has been tested for clarity and utility among health care professionals, office workers., hospital cafeteria workers, and eighth grade students.

The document is the size of a medical chart and is recommended for use by all competent adults as part of their routine health maintenance and preventive care. Advance care planning documents should become part of every patient's permanent medical record, can be updated as desired, and may be stored in a central registry; whereupon, healthcare providers, facilities, and emergency medical teams can have immediate access.

The document can be obtained for free by calling Project GRACE (Guidelines for Resuscitation And Care at End-of-Life), or can be downloaded, at no cost, from the Project GRACE website at www.p-grace.org.

Also, the Advance Care Plan is included in my *Life and Death on Your Own Terms*, a handbook of how to prepare for medical care at the end-of-life. This book is available in all major bookstores or by contacting the publisher, Prometheus, at 800-421-0351. Proceeds from the sale of the book support Project GRACE.

Access to Health Care for the Hearing-Impaired: Part II

MELINDA J. BROWN, J.D.
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Hearing-impaired individuals owe it to themselves to make sure that despite problems they might experience communicating, they receive adequate information from their health care providers, including doctors and hospitals, concerning their health care needs. They can do this is through effective communication, appropriate selection of physicians and judicious use of their own medical records. Such steps can aid them in gaining greater access to quality health care and in improving the quality of their lives.

Effective Communication

Effective communication between the deaf individual and the health care provider is the first step in getting quality medical care, and it is a critical step. The foundation for effective communication must be laid first between the hearing-impaired individual and the patient's individual health care provider (doctor, dentist, nurse, pharmacist, or other health personnel). It is critical that the hearing-impaired individual tell medical personnel of his or her hearing disability. The hearing-impaired individual will need to explain to the medical personnel how they can best communicate with him or her. If speech reading, for example, such individuals must inform the medical staff that they must see the faces of medical staff at all times when the medical staff is speaking to them.

Federal regulations require that any office constituting a public accommodation furnish appropriate auxiliary aids and services where necessary to ensure effective communication with individuals with disabilities.[1] Effective communication with a person with a hearing impairment does not involve simply talking to that person. It may require communication through means other than talking. Moreover, effective communication, even if verbal, requires more than just words being spoken; it requires dialogue.

Thus, hearing-impaired individuals need to understand that they are entitled to request interpreters – either sign language interpreters or oral interpreters.[2] Interpreters are to meet Department of Justice standards, for example by having the ability to interpret "effectively, accurately and impartially."[3] Neither family, nor friends, nor non-professional sign language interpreters meet Department of Justice standards. Family and friends, for example, are not impartial, and they may lack familiarity with medical terminology. Some non-professional sign language interpreters do not sign accurately and are unfamiliar with various deaf modes of communication.

While hearing-impaired individuals must tell health care providers of their communication preferences, and may in fact prefer a highly qualified interpreter, they may not always get their preferences. A doctor need not always provide interpreters for deaf patients.[4] Rather, a person, office or entity covered by the ADA or the Rehabilitation Act must provide means of effective communication. There are several auxiliary aids and services that could be used to aid in effective communication. They include qualified interpreters, other sign or oral interpreters, computer-aided transcription services, written materials, assistive listening systems, and other effective methods of making aurally delivered materials available to individuals with hearing impairments.[5]

Two main factors figure in the determination of whether the services of a qualified interpreter are required. This determination should be made on the basis of the nature and severity of the patient's aliment, and the patient's literacy level.[6]

A public accommodation such as a doctor's office may deny an auxiliary aid only if it can demonstrate that providing the auxiliary aid would fundamentally alter the nature of the service or would constitute an undue burden or expense.[7] A doctor who refuses to provide interpreting services must show that effective communication can be achieved by other means.[8]

Health care providers would do well to remember that effective communication, while vital for patients, also benefits them. Health care providers may be liable for malpractice when a medicine is prescribed or a treatment administered without knowing the deaf person's medical history or without obtaining informed consent.[9]

This article is the second in a three-part series on access to health care for the hearing-impaired. This article covers the hearing-impaired individual's responsibilities in ensuring that he or she gets quality medical care for him or herself and his or her family.

Part I provided an overview of the importance of the issue and discussed the legal rights of the hearing impaired. Part III will address clinicians' and hospitals' responsibilities to their hearing-impaired patients.

Appropriate Selection of Health Care Provider

The next step in access to quality medical care for a hearing-impaired patient is in the appropriate selection of a doctor. The hearing-impaired patient should select a primary care physician and visit that physician before actually requiring a visit for medical reasons. By selecting the doctor ahead of time, the patient can review all those on the list from which he or she can choose, and can see if he or she is comfortable with the doctor chosen. Further, the doctor chosen will also get the chance to know the patient and his or her communication needs before actual illness.

When selecting a primary care physician, hearing-impaired patients should use the TDD/TTY via Relay Station. This is the best method to use because the relay operator will explain to the doctor's office that the person calling

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has a hearing impairment. The patient should ask up front whether the doctor is willing to accept deaf patients. Generally, doctors have a right to refuse to accept a patient at the inception of a physician-patient relationship. The law assumes that a physician must accept a patient voluntarily before the physician-patient relationship is legally binding.[10] Thus, if a particular doctor is unwilling to accept deaf clients as patients, the hearing-impaired patient should call another doctor. (Even if the patient might be able to use the ADA or the Rehabilitation Act as a club to force a doctor to accept him or her as a patient, the patient is more likely to actually achieve effective communication with a physician who has been willing from the start to take on deaf patients.) When selecting a doctor, the patient also should be aware of the hospital with which the doctor is affiliated, and ideally should attempt to proactively determine whether that entity has in place adequate procedures for dealing with hearing-impaired patients.

Before the physician-patient relationship is established, the hearing-impaired individual must tell the doctor of his or her communication needs in person, at the first appointment. Such patients must tell the doctor, for example, that they may require more time for visits because of their communication needs.

Additionally, a hearing-impaired person who has already established a relationship with a doctor might investigate the possibility of faxing questions to the doctor's office. Each such fax request should be limited to one page, including the questions and space for the physician to write the answers. If this method of communication is acceptable to a physician, it can be effective, but the patient should be aware that patient-physician confidentiality with the fax method is limited. (The communication is written and any medical staff personnel can read it.) There are a few doctors that will accept e-mail questions, but some of them may charge for that e-mail. The patient should always discuss with the doctor beforehand the best method of communication with him or her regarding health-related questions outside the office visit setting.

Judicious Use of Medical Records

Finally, the hearing-impaired patient can make judicious use of medical records in effectively communicating about his or her health. Medical records are generated every time a patient goes to a doctor's office or a hospital (even if only for the drawing of blood or an overnight stay). Those medical records are a valuable source of information. Hearing-impaired patients especially should request copies of those records and read them carefully, looking up unfamiliar words in a good medical dictionary. (There may be a small charge for copying.) The deeper understanding that can result from reading medical records can assist in communication, especially regarding medical terminology.

Written records help in accessing medical care because they can be copied and put into the patient's file at each new doctor's office. The doctor can read the written records quickly, rather than relying solely on taking an oral history when still becoming familiar with a hearing-impaired person's modes of communication. Maintenance of a written medical history – including illnesses, medications, drug reactions, allergies, past surgeries, immunizations, and names of doctors – also can save time in an emergency situation when the patient may not be able to communicate effectively with medical personnel.

With effective communication, careful choice of physician and judicious use of their medical records, hearing-impaired individuals themselves can take great steps toward improving their access to medical care and the quality of care they receive.

Notes

1. 28 C.F.R. §36.303(c) (2001).
2. Sumes v. Andres, 938 F. Supp. 9 (D. D.C. 1996) (physician refused to treat deaf woman due to deafness).
3. 56 Fed. Reg. 35,553 (1991).
4. DISABILITY COMPLIANCE BULLETIN, WHEN ARE INTERPRETERS REQUIRED?, VOL.19, NO.1, OCT.20, 2000. Explaining the DOJ rule implementing Title III of the statue, at 28 C.F.R. § 36.303(c)(2001).
5. 28 C.F.R. §36.303(b)(1) (2001).
6. See note 27.
7. 28 C.F.R. §36.303(a) (2001).
8. NATIONAL ASSOCIATION OF THE DEAF, LEGAL RIGHTS: THE GUIDE FOR DEAF AND HARD OF HEARING PEOPLE, at 96 (5th Edition 2000).
9. Id. at 96.
10. Reyonds v. Decatur Memorial Hosp., 660 N. E.2d 235 (Ill. App. Ct. 4th Dist. 1996).

Electronic Prescription Monitoring Programs: An Update

DAVID B. BRUSHWOOD, R.Ph., J.D.
Professor, Pharmacy Health Care Administration
University of Florida

TALLAHASSEE – The Florida Legislature has twice defeated a proposal to establish a state electronic Prescription Monitoring Program (ePMP). Modified significantly many times over the course of several months (so much so that legislators must have had difficulty knowing exactly what they were voting on), the proposed ePMP legislation would have required pharmacists to upload controlled substance dispensing data to the Department of Health every 15 days. These data would include patient names, drug names and physician names. The data would be reviewed to determine whether physicians, pharmacists or patients identified in the data should be prosecuted or disciplined for illegal prescribing, dispensing or using controlled substances.

In the second special legislative session called by Governor Bush, this legislation was viewed by some as one of five "must pass" bills under the governor's legislative agenda. It is the only one of the five that did not pass. Floor debate in the Florida House of Representatives focused on the confidential nature of these data and the potential problems with the release and inappropriate use of the confidential information.

It is highly likely that a proposal for an ePMP will resurface in the 2003 Legislature. This type of program is viewed as the gold standard for drug abuse prevention by some drug regulators. The reality is that there are no empirical data validating the effectiveness of ePMPs in preventing substance abuse in any of the 18 states that have these programs. There also are no empirical data validating the claim that ePMPs have no "chilling effect" on appropriate and necessary pain management. Unfortunately, the claims that ePMPs reduce substance abuse and do not adversely affect legitimate medicine are perceived as being valid because they are oft repeated without challenge. But no empirical studies have been done to validate either claim.

> ***'It's time to demand evidence that ePMPs in other states have actually reduced substance abuse without having a chilling effect on appropriate pain management.'***

In the pharmaceutical industry, any claim that a new drug is effective and has no side effects would be challenged and immediately rejected if there were no empirical evidence to support the claim. It is curious that regulators willingly accept assurances that a new drug use program is effective and has no side effects, without empirical data to support the claim.

The American Alliance of Cancer Pain Initiatives has recently issued a statement on State Prescription Monitoring Programs (www.aacpi.org). That group joins a list of groups that have expressed concern about ePMPs without daring to actually oppose them. It would be a bold move for an organization to express outright opposition to ePMPs, because opposition to strong drug control measures makes one seem like a naïve, bleeding-heart liberal who is soft on crime.

The time will come for those in Florida who value the privacy of patient care records, and who understand the barriers regulation can pose to effective pain management, to step forward and demand evidence that ePMPs in other states have actually reduced substance abuse without having a chilling effect on appropriate pain management. This is not a position that is in opposition to law enforcement. But it is a position that urges a balancing of law enforcement with patient care.

Judge Tosses Right-to-Know Abortion Law

SUSAN SPENCER-WENDEL
Palm Beach Post Staff Writer
Tuesday, September 17, 2002

WEST PALM BEACH – In a blow to anti-abortion activists, a Palm Beach County judge struck down a law mandating what abortion doctors must tell and provide potential patients.

The decision, by Circuit Judge Ronald Alvarez, further freezes the law known as the Women's Right-to-Know Act. The act, challenged legally since its passage in 1997, dictated a generic checklist of things doctors must tell a patient with little regard for her individual situation. It required doctors to tell women the nature and risks of an abortion "that a reasonable patient would consider material" to making a decision, the age of the fetus and the medical risk of taking the pregnancy to term.

Alvarez wrote that the law infringes on a woman's ability "to receive her physician's opinion as to what is best for her considering her particular circumstances. This is constitutionally impermissible," Alvarez said.

"The handcuffs are off the doctors," said attorney Louis Silber, who represented Presidential Women's Center of West Palm Beach in its fight to overturn the law. "It removes a significant barrier or obstacle in the process."

What is particularly offensive is that a woman with an abnormal fetus or a raped woman would have to sit with a doctor and discuss taking the pregnancy to full term, Silber said.

After Women's Right-to-Know Act was passed, the Presidential Women's Center sued the Florida Department of Health, the agency that would discipline doctors for failing to perform the tasks. A local appeals court in 1998 granted a temporary block of the law, which has remained in force since, meaning the law has never been put in practice.

After the 4th District Court of Appeal's decision, the case sat for years until the Florida Attorney General's Office and Department of Health renewed their fight for the law, which eventually led to Alvarez's decision.

Silber called the state's continued fight the most vicious attack on women's clinics and reproductive rights he's seen in 14 years of abortion-rights litigation. Alvarez's permanent injunction Friday sets the stage for a higher legal battle.

Department of Health General Counsel William Large said the agency respectfully disagrees with the opinion and will appeal it again to the 4th District Court of Appeal. From there it would move to the Florida Supreme Court.

The department is trying to protect the women of Florida, ensuring them the most information possible before receiving an abortion, Large said. Women who seek abortions are an extremely vulnerable population who rarely will take recourse when something goes wrong. The law protects them he said.

"I don't believe there ever were any handcuffs on any physicians with respect to this statute," Large said.

Abortion-rights activists opposed the law saying it created a different set of informed consent standards for abortion providers than for regular doctors.

The president of the Palm Beach County Right to Life League, Richard Giesman of Palm Beach Gardens, said even then it wasn't enough. "If I'm going for open heart surgery, I want to hear all about it. I would want to see pictures of it. I want to understand everything," Giesman said. "We're doing an injustice to anyone not giving them the full information to make an informed decision."

Planned Parenthood chief Lillian Tamayo said it's not about withholding information from abortion seekers, but about creating a different standard for abortion providers than for other doctors.

"Criminal penalties could be expected or placed upon physicians for failing to provide certain kinds of information," Tamayo said. "That's wrong."

'Living Will Day," and New Programs Boost FBN

(Continued from page 1)

- Aventura Chamber of Conference
- Aventura Hospital and Medical Center
- Aventura Marketing Council
- Florida Partnership for End-of-Life Care
- University of Miami Ethics Programs

Moreover, a suite of area law firms provided pro-bono advice to attendees, many of whom had never executed an advance directive. The lawyers and firms: Jay R. Beskin, Esq., Fromberg, Perlow & Kornik, P.A., and M. Keith Marshall, Esq.

Perhaps the highlight was when State Sen. Margolis, acting chair of the Miami-Dade Board of County Commissioners, hailed the effort and presented an official county-wide proclamation of April 13 as "living will day." It was apparently the first time a "living will day" had been declared in Florida.

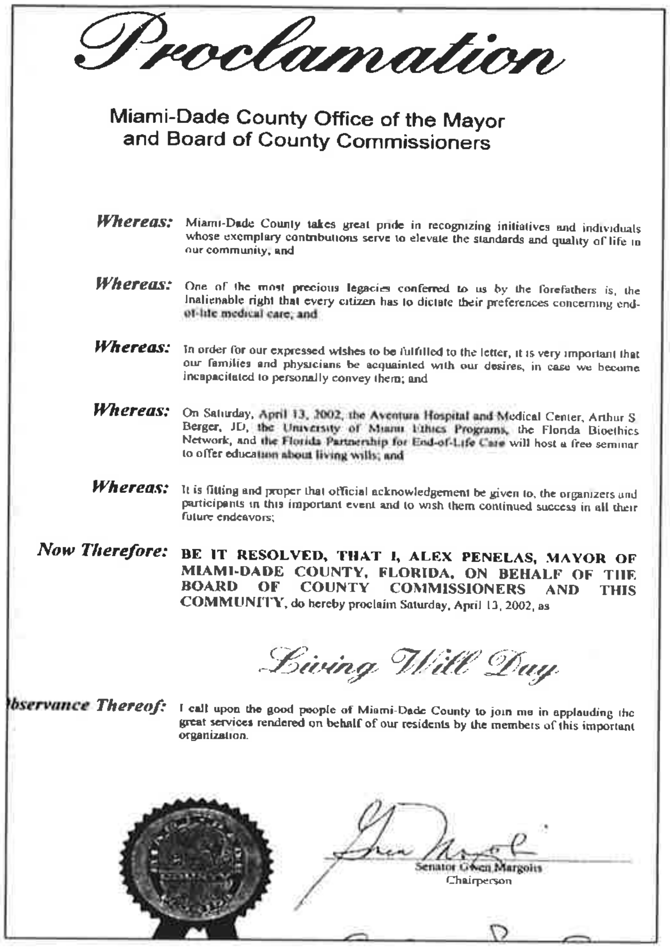
Berger and others allowed as how the success in Aventura could provide a model for similar efforts in other communities.

Elsewhere in Florida, the FBN sponsored its second ethics conference in Port Charlotte, again drawing some 150 people for presentations on end-of-life care, HIPAA and patient privacy and assisted suicide. The Aug. 23 program demonstrated again the need for high-quality ethics education around the state.

In March, the FBN teamed with the University of Miami Bioethics Program for what was likely the largest ethics conference ever in Florida – a program that saw keynote talks from UM President and HIPAA framer Donna E. Shalala and physician-ethicist Steve Miles. Some 400 people attended. The next Southeast Florida program is set for March 7, 2003; look for more on HIPAA and special sessions on aging and dementia.

At its best, the FBN reaches out to health professionals and others who crave contact with others similarly situated – it is, after all, a *network*. In keeping with that approach, an unprecedented conference has been scheduled for Jan. 10 in Tallahassee.

Dubbed "Bioethics in the Capital," the program will feature a keynote talk by Harry Lee Anstead, Chief Justice of Florida's Supreme Court, a number of presentations on end-of-life care, an "Ethics in Florida" overview, and sessions on child advocacy, DNA banking, ethics committee operations, and mental incapacity in jails and prisons. FBN members receive tuition reduction; students attend free.



Proclamation

Miami-Dade County Office of the Mayor
and Board of County Commissioners

Whereas: Miami-Dade County takes great pride in recognizing initiatives and individuals whose exemplary contributions serve to elevate the standards and quality of life in our community; and

Whereas: One of the most precious legacies conferred to us by the forefathers is, the inalienable right that every citizen has to dictate their preferences concerning end-of-life medical care; and

Whereas: In order for our expressed wishes to be fulfilled to the letter, it is very important that our families and physicians be acquainted with our desires, in case we become incapacitated to personally convey them; and

Whereas: On Saturday, April 13, 2002, the Aventura Hospital and Medical Center, Arthur S Berger, JD, the University of Miami Ethics Programs, the Florida Bioethics Network, and the Florida Partnership for End-of-Life Care will host a free seminar to offer education about living wills; and

Whereas: It is fitting and proper that official acknowledgement be given to, the organizers and participants in this important event and to wish them continued success in all their future endeavors;

Now Therefore: **BE IT RESOLVED, THAT I, ALEX PENELAS, MAYOR OF MIAMI-DADE COUNTY, FLORIDA, ON BEHALF OF THE BOARD OF COUNTY COMMISSIONERS AND THIS COMMUNITY**, do hereby proclaim Saturday, April 13, 2002, as

Living Will Day

bservance Thereof: I call upon the good people of Miami-Dade County to join me in applauding the great services rendered on behalf of our residents by the members of this important organization.

Senator Gwen Margolis
Chairperson

Whereas and therefore: Proclamation of "Living Will Day" in Miami-Dade County, signed by Sen. Gwen Margolis and Mayor Alex Penelas. Here is the text of the proclamation:

Whereas: Miami-Dade County takes great pride in recognizing initiatives and individuals whose exemplary contributions serve to elevate the standards and quality of life in our community; and

Whereas: One of the most precious legacies conferred to us by the forefathers is, the inalienable right that every citizen has to dictate their preferences concerning end-of-life medical care; and

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Whereas: It is fitting and proper that official acknowledgment be given to the organizers and participants in this important event and to wish them continued success in all their future endeavors;

Now Therefore: Be it resolved that I, Alex Penelas, Mayor of Miami-Dade County, Florida, on behalf of the board of County Commissioners and this community, do hereby proclaim Saturday, April 13, 2002, as Living Will Day.

Schiavo Case Enters New Phase — Again

(Continued from page 1)

sion of a six-day hearing.

"The overwhelming nature of evidence shows that Terri is in a persistent vegetative state without hope of recovery. It's a certainty," Mr. Schiavo's attorney, George Felos, told *Florida Bioethics.*

That's not the case, says Schindler attorney Pat Anderson, arguing that Ms. Schiavo reacts to her parents with tears and smiles, moves her head and moans. "She's not a candidate for death under Florida law," Anderson said shortly before she filed a motion for appeal.

During the October trial, which garnered national attention, a crowd of protesters gathered each day outside the courthouse to support keeping Ms. Schiavo on life support.

Many belonged to disabled or pro-life groups and waved signs reading "No Execution by Starvation" or "Disability is Not a Crime."

Inside the courtroom, Judge Greer heard the opinions of five doctors: two chosen by the Schindlers, two selected by Mr. Schiavo and a fifth chosen by the judge.

Anderson focused much of her argument on the testimony of Clearwater neurologist William Hammesfahr, who claimed that Ms. Schiavo is aware and responsive.

A video of his examination supporting this claim was shown in court. In one clip, Ms. Schiavo appeared to be reacting to her mother. In another, she is seen listening to piano music and, to some, opening and closing her eyes on command.

Judge Greer's tie-breaking doctor, however, sided with those selected by Mr. Schiavo. All three concurred that any reactions Ms. Schiavo shows to pain or other stimulus is involuntary and unconscious.

In a nine-page order, Judge Greer finally concluded: "Viewing all the evidence as a whole, and acknowledging that medicine is not a precise science, the court finds that the credible evidence overwhelmingly supports the view that [Terri] Schiavo remains in a persistent vegetative state."

That finding upholds his earlier decision when, in April 2001, he first ordered the feeding tube removed. Then, he based his ruling on Mr. Schiavo's testimony that Ms. Schiavo once told him she would not want to be kept on life support. Ms. Schiavo left no written advance directive.

The Schindlers petitioned the case all the way to the U.S. Supreme Court, but it refused to intervene.

At one point last year, the feeding tube was disconnected on Judge Greer's orders, only to be reinserted on another judge's orders.

This time around, a similar scenario could very well play out again.

Anderson says the basis for the latest appeal will rest on a newly discovered bone scan taken 13 months after Ms. Schiavo's heart malady, showing fractures to her ribs, back, knees, ankles and right thigh. Anderson says it indicates her client was "a victim of severe physical abuse," and alleges that Mr. Schiavo might have abused her prior to her collapse.

The long and difficult case of Terri Schiavo has evolved into a bitter clash involving family members, partisans, advocates — and the courts.

Anderson introduced the evidence in an emergency motion filed only a week before Judge Greer's ruling in November. "I don't see any court allowing her to die without full briefing on the merit of the argument," Anderson said.

Felos dismissed the abuse allegations as "garbage," saying they're based on a misinterpretation of many tests the parents have had for three years.

To date, doctors blame Ms. Schiavo's heart attack on a potassium imbalance possibly brought on by bulimia. She received a $700,000 malpractice award in 1993 based on a suit that doctors at the time failed to conduct tests that would have revealed her low potassium level. Mr. Schiavo also received a separate $300,000 payout.

Now, the Schindlers say, Mr. Schiavo is motivated by the hope of inheriting whatever is left of Ms. Schiavo's award – a reported $140,000 or less.

"It's a tragedy to believe an effort to reach a peaceful end to someone's life is being wrapped in such ugliness," said Kathy Cerminara, associate professor and director of the Health Law Master's Program at Nova Southeastern University in Davie and co-author of the standard legal reference *The Right to Die* (Aspen Publishing Co.).

She said she believes Ms. Schiavo would not be happy over the feud. "At some point, attorneys must discuss with their clients whether their wishes are reasonable," she said. And unreasonable wishes do not in themselves impose duties on legal counsel.

In the end, Cerminara says, the case illustrates the importance of drawing up a living will ahead of time.

"Had there been an advance directive in this case, there would have been less room for argument about whether treatment should be terminated."