Florida Bioethics Network FBN

Florida Bioethics

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Legislature Clarifies, Corrects Aspects of State's Advance Directive Statute

TALLAHASSEE – The Florida Legislature has made a number of important changes to the law that governs living wills and other advance directives. Led by Sen. Ron Klein (D-Delray Beach), the Legislature moved to clarify and correct a number of components of Florida Statute 765, in several respects trying to adopt the recommendations of the state's End-of-Life Care Workgroup.

Many of those recommendations were shaped as part of the statewide Partnership for End-of-Life Care, one of several Robert Wood Johnson Foundation-sponsored efforts around the country. The FBN is a key component of the Florida Partnership.

Sen. Ron Klein

One of the more significant changes is in the definition of "end stage condition." The standard of medical judgment for determining a patient to be in an end stage condition was reasonable medical certainty, whereas the standard for determin-

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Inside this issue

DNA Tests Spark Challenge To Morality of Death Penalty

JASON BORENSTEIN, Ph.D.

As the number of exoneration cases grows, questions about criminal proceedings and the morality of the death penalty have regained the spotlight.

In recent years, several individuals convicted through the criminal legal system, some of which who served time on death row, have been freed as a result of DNA testing. Evidence from DNA testing continues to undermine the veracity of eyewitness reports, expert witness testimony, and the confessions from alleged criminals.

This problem has noticeably affected legislation and generated several inquires into past legal cases.

Within the past few months, Broward County law

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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 Ethics Calendar

Please e-mail submissions to ethics@miami.edu

HOSPICE OF SOUTHWEST FLORIDA

August 24, 2001, Port Charlotte — Ethical Issues at the End of Life, a special regional workshop by the **Florida Bioethics Network** and Hospice of Southwest Florida. 941-929-2313.

September 12-14, Lake Buena Vista — Florida Hospices: Unlimited Possibilities, Florida Hospices and Palliative Care, Inc., and Florida Partnership for End-of-Life Care. 850-878-2632

October 18-21, 2001, Miami — Extreme Ethics: Especially Difficult Challenges in Epidemiology and Human Subjects Research, University of Miami Ethics Programs and the National Institutes of Health. www.miami.edu/ethics; 305-243-5723.

October 21-24, Delray Beach — National Guardianship Association Annual Conference (including a number of sessions on ethics and guardianship). 520-881-6561.

December 10-13, 2001, Clearwater Beach — Ethics in Research: An Intensive Training Course Focusing on Behavioral Health Sciences, University of South Florida Department of Mental Health Law & Policy and the National Institutes of Health. www.fmhi.usf.edu/mhlp; 813-974-7623.

March 1, 2002, Fort Lauderdale/Hollywood — Clinical Ethics: Debates, Decisions, Solutions (**Florida Bioethics Network** spring conference and University of Miami 10th annual conference). Focus sessions to include a HIPAA track, including standards for staff education under HIPAA. www.miami.edu/ethics; 305-243-5723.

Correction

In the last issue we gave the wrong Web address for Nova Southeastern University's new online master's of health law program. The correct Website is http://www.mhl.nsulaw.nova.edu. The Shepard Broad Law Center is the first American Bar Association-accredited law school in the country to provide master's-degree-level online health law education to non-lawyers.

FBN Board Member's Dissertation Focuses on Hospice

TAMPA — Hana Osman, a longtime FBN board member, has been awarded a Ph.D. by the University of South Florida for her dissertation examining the processes of end-of-life decision making in a LifePath Hospice population in Hillsborough County, Florida.

LifePath Hospice is a residence-based program that offers palliative care to patients who have a life-limiting illness. The purpose of the research was to study patient and family processes of end-of-life decision making. Accepting or declining resuscitation is the specific decision of interest, a decision that is routinely discussed with patients during the admission to LifePath Hospice.

Providing informed consent occurs by following either an individual-based model that is grounded in the ethical principle of preserving patient autonomy, or a family-based model that espouses a communitarian approach to decision making. The family ecology theory was used to provide the theoretical framework to organize and to interpret the findings.

Dr. Osman's study was conducted using qualitative methods of participant observation, recording of field notes to document the observation, semi-structured interviewing, and data collection from the LifePath Hospice medical records and electronic data bases. Results of the research suggest that in this sample, patients' life histories and values, individual and family patterns of decision making, personal life experiences, medical condition, medical prognosis, and the level of understanding of the process of resuscitation contributed to patients' choice of accepting, or declining, resuscitation.

Several implications for clinical practice are generated by the research:

a) the health care provider who is most familiar with the patient's medical condition may be the most appropriate person to obtain informed consent;
b) provide staff training to shift the focus from obtaining a signature on the do-not-resuscitate order to education about resuscitation;
c) discuss resuscitation within the context of patients' values;
d) implement staff education that stresses thorough understanding of the technical aspects of resuscitation;
e) provide the clinical staff with education that emphasizes accuracy about what health care planning documents mean, and when they become effective.

DNA Tests Challenge Morality of Death Penalty

(Continued from page 1)

enforcement agencies decided to conduct a review of DNA evidence in the cases of 28 death row inmates. Ironically, the decision to review these cases occurred near to the time when the Florida Legislature decided to allow Floridians to vote on an amendment that would add the death penalty to the state Constitution. The constitutional amendment will be placed on the November 2002 Florida ballot.

The review by Broward County was likely sparked by the discovery that two individuals, Frank Lee Smith and Jerry Frank Townsend, did not commit the crimes for which they have been convicted. Smith had been convicted of murdering an eight-year-old child in 1985. He died last year while serving his time on death row. He was exonerated posthumously after DNA testing showed that another man, Eddie Lee Mosley, committed the murder. Mosley has also been linked to murders for which Townsend had been convicted. Townsend remains in prison and it is unclear whether the DNA evidence will lead to his release.

In response to problems afflicting criminal proceedings, the Florida legislature has approved a bill that would give defendants more access to DNA testing. If the DNA bill is signed into law, it would allow a person convicted of a crime to request for DNA testing up to two years after his/her sentence is finalized. In order to be granted a DNA test, a motion must be filed with a court detailing how the evidence could help to establish the convicted person's innocence. Several states, such as New York, Illinois and Minnesota, have already have enacted similar post-conviction DNA statutes.

The problem of faulty convictions is certainly not unique to Florida. Within the past year, Illinois Governor George Ryan issued a moratorium on executions in his state and created a panel to investigate death penalty proceedings.

In Oklahoma, Joyce Gilchrist has been accused of providing misleading courtroom testimony and misidentifying evidence in criminal cases. Gilchrist worked as a scientist for the Oklahoma City police laboratory and has been involved in approximately 3,000 cases. Gilchrist is currently being investigated by the state and a number of her cases are being reviewed.

2001 Legislature revises advance directive statute

(Continued from page 1)

ing a patient to be terminally ill was reasonable medical probability. The Legislature revised the standard of clinical judgment for determining "end stage condition" to "reasonable degree of medical probability."

The original phrase in the end stage condition definition – one which completely baffled most people – was "indicated by incapacity and complete physical dependency." This phrase has been dropped. The adjective "irreversible" has been added to modify condition, and "progressively" has been inserted to modify "severe." Finally, the word "medically" has been deleted from before the word "ineffective."

While these changes are noteworthy, they will be seen by some experts as part of a long-term effort to eliminate the statutory tests and hurdles to patients having true control of their end-of-life care. Florida law requires that patients who wish to use a living will to refuse treatment must meet one of three tests. They must either have a "terminal condition" or an "end-stage condition," or be in a persistent vegetative state. These tests, which many patients, families and health professionals have found onerous, have remained in statute over the years because of political considerations. The tests remain in the statute.

Another key change involved providing a definition of palliative care and specifying a long list of what palliative care must include (see box on Page 5). Taken together, these assurances might represent some of the most positive and progressive legislative support for palliative care in the country. To be sure, some provisions will require time to evaluate in context. But one provision – that palliative care must include the "Assurance that organizational mechanisms are in place to evaluate the availability and quality of end-of-life, palliative, and hospice care services, including the evaluation of administrative and regulatory barriers – could go far in elevating the standard of care for palliative care.

Significantly, the Legislature also added "best interest" as a legitimate basis for withholding and withdrawing life sustaining treatment, if there is no indication what the patient would have wanted. This applies to both the surrogate (designated by the patient) and the proxy (determined by statute).

The new language might represent some of the most positive and progressive legislative support for palliative care in the country.

FS 765.205 now stipulates that surrogates shall "Consult expeditiously with appropriate health care providers to provide informed consent, and make only health care decisions for the principal which he or she believes the principal would have made under the circumstances if the principal were capable of making such decisions. If there is no indication of what the principal would have chosen, the surrogate may consider the patient's best interest in deciding that proposed treatments are to be withheld or that treatments currently in effect are to be withdrawn." FS 765.401, governing proxies, was similarly modified.

The changes took effect July 1, 2001.

The Florida Bioethics Network has an explicit role in Florida law. Chapter 765 – "Health Care Advance Directives" – requires that in certain cases (involving patients in persistent vegetative states who have guardians but no advance directives and no kin) that treatment termination decisions be evaluated by an ethics committees and, in the absence of such an institutional committee, be scrutinized by a "community-based ethics committee approved by the Florida Bioethics Network."

That provision was introduced in 1999.

Doris Herbert, Florida Living Will Pioneer, Dies at 93

DUNEDIN – (AP) – Doris Herbert, a pioneer of Florida's living will, has died at age 93. Herbert died March 24 at ManorCare Health Services where she had been for the past year following a series of strokes.

Her attorney, George Felos, said that Herbert had a living will.

"She was very specific," said DeeAnn Foster-Robertson, who was her power of attorney and health care surrogate for the last two years.

Hospice was called in three days before she died, Foster-Robertson said.

"She did not want to be taken back to the hospital and attached to tubes, even for dehydration."

In the 1980s, Herbert fought through the courts on behalf of Estelle Browning, her second cousin, who refused life-prolonging medical procedures in her 1985 living will. Herbert was her cousin's guardian.

A 1986 stroke left Browning paralyzed and attached to feeding tubes. Herbert began a legal battle in 1988 to remove the tubes. But Browning, 89, died still connected to the tubes before the case was settled.

Two years later, the Florida Supreme Court cited a state constitutional right to privacy and ruled caregivers may withhold food and water from an incapacitated person even when death is not imminent.

The ruling also granted the right to die to people who have stated they don't want to be fed indefinitely through a tube.

Felos said Herbert, who was in her 80s, at the time showed courage to pursue her cause despite opposition and personal threats.

"She showed a lot of Yankee spunk to go through that," Felos said. "But the result benefited countless Floridians."

In making advance funeral arrangements, Herbert made no request for an obituary and news of her death didn't become known until later.

Herbert was born in Pawtucket, R.I., and in 1982 moved to Dunedin in west central Florida from Albany, N.Y.

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State law has new language in support of palliative care

The following section was inserted by the 2001 Legislature into Florida Statutes Chapter 765.102

(5) For purposes of this chapter: (a) Palliative care is the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. Palliative care is especially suited to the care of persons who have incurable, progressive illnesses. (b) Palliative care must include:

1. An opportunity to discuss and plan for end-of-life care.
2. Assurance that physical and mental suffering will be carefully attended to.
3. Assurance that preferences for withholding and withdrawing life-sustaining interventions will be honored.
4. Assurance that the personal goals of the dying person will be addressed.
5. Assurance that the dignity of the dying person will be a priority.
6. Assurance that health care providers will not abandon the dying person.
7. Assurance that the burden to family and others will be addressed.
8. Assurance that advance directives for care will be respected regardless of the location of care.
9. Assurance that organizational mechanisms are in place to evaluate the availability and quality of end-of-life, palliative, and hospice care services, including the evaluation of administrative and regulatory barriers.
10. Assurance that necessary health care services will be provided and that relevant reimbursement policies are available.
11. Assurance that the goals expressed in subparagraphs 1.-10. will be accomplished in a culturally appropriate manner.

Schiavo Case Rends Family; Absence of Living Will an Issue

MAYA BELL
Orlando Sentinel

ST. PETERSBURG — What would Terri want? Would she want to spend the rest of her life curled in a bed, fed by a tube, unable to talk or think?

Or would she want the feedings stopped so she could slip from her 11-year-old void and die?

Terri can't answer for herself. But as the 37-year-old woman lies in a tranquil Pinellas Park hospice, a legal firestorm rages outside over whether she should live or die.

Her parents say their daughter's husband is fighting to halt the twice-daily feedings that keep her alive to inherit what's left of the hundreds of thousands of dollars she won in a malpractice suit eight years ago.

Michael Schiavo throws back the accusation: He says Robert and Mary Schindler are driving him to divorce the woman he married 17 years ago so they can control her assets. Neither side talks to the other. So this most private of family matters has been thrust into the courts, with the latest legal salvo due today. It's also playing on the airwaves like a tawdry daytime soap.

"He stood in front of a malpractice jury and pleaded with them to award Terri money and vowed he would take care of her for the rest of his life," Terri's father said. "Then eight months later, he tried to kill her by instructing her caretakers not to medicate her for a potentially fatal infection."

Schiavo, 38, struck back on a Tampa drive-time radio show. He accused his in-laws of failing to visit their daughter for months because they were mad about not winning a cut of the malpractice award.

"It has nothing to with money," the respiratory therapist insisted. "This has to do with Terri's wishes. Terri is my wife, and it breaks my heart that is has to be like this."

It didn't have to be.

No living will

The family feud over Terri, who collapsed from a heart attack and endured five critical minutes without oxygen, could have been avoided had she taken steps to make her wishes clear. But as her husband said, "At 25 years old, who thinks about that?"

Planning for the unthinkable is not something most Americans, especially those Terri's age, even consider, but experts say her case is a persuasive argument for doing so. "The lesson here is make sure your loved ones know what you want either by appointing a surrogate or executing a living will," said Kenneth Goodman, co-director of the Florida Bioethics Network. "Advanced directives are not just for old people. They're for everyone."

The other certainty was summed up in January when the 2nd District Court of Appeal in Lakeland cleared the way for Schiavo to halt the hydration and nutrition pumped into his wife's stomach each morning and night. The three-judge panel, finding no evidence that Schiavo or the Schindlers are motivated by greed, had this to say:

Father: Terri changes

Terri's father says Schiavo, who has been engaged to another woman for the past six years, was a dedicated husband before he won the malpractice suit against one of Terri's doctors in 1993. The jury awarded Schiavo damages for loss of his wife's companionship and Terri more than $1 million for her care and comfort.

But as soon as the money was placed under Schiavo's control, Schindler insists, his son-in-law changed. No longer was he the devoted husband who changed Terri's diapers, who fixed her hair, who made sure she was taken to the museum or to the mall.

And no longer, Schindler says, did Schiavo spend Terri's funds on the rehabilitative or experimental treatments that her family still believes could draw her out of her silent cocoon. Neither did they have the means to hire their own experts to prove that was possible.

"That's what has driven our family to fight so hard," Schindler said. "She's not a vegetable as she's being portrayed. She's alive. She's responsive, and there's a possibility now that she could be rehabilitated."

They cling to that hope because Terri's body still works. No machine keeps her alive. She breathes on her own. Her eyes are open by day.

"She recognizes mostly my wife," Schindler said. "She gets a grin on her face from ear to ear. Sometimes she'll be sobbing. My wife will soothe her like a child."

But doctors have said the Schindlers are mistaking involuntary reflexes for cognition. Terri is in a persistent vegetative state, they say. Her body may function fine, but her brain doesn't, and never will.

It was acceptance of that reality that Schiavo says led him to give up on his wife. That and the casual conversations he said they had while watching TV or attending a funeral. Terri, he swore in court, said she would never want to be kept alive artificially.

That satisfied Pinellas-Pasco Judge George Greer. More than a year ago, Greer ruled that Schiavo had the right to make decisions for his wife and could halt the feedings. In April, after the last appeals court agreed, Schiavo ordered her feeding tube clamped; Terri's death appeared imminent.

Then, making a rare public comment, Schiavo called 93.3 FM (WFLZ) in Tampa and, in a tear-choked voice, explained his reasons. "Terri's never improved in 11

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Financial Considerations Complicate Case Still Further

KATHY CERMINARA, J.D.
Nova Southeastern University

The legal case pending in the Tampa/St. Petersburg courts, *In re Guardianship of Schiavo*, serves as a reminder that end-of-life decision making is incredibly difficult for, and can in fact divide, families, especially when financial considerations appear to be part of the equation.

The case, which was still pending in the courts, involves a 37-year-old woman, Theresa Schiavo, who has been in a persistent vegetative state (PVS) for more than 11 years, since she suffered a heart attack that deprived her brain of oxygen for more than five minutes. Theresa's husband wishes to withdraw her artificial nutrition and hydration, saying that she would have refused that nutrition and hydration in this situation. Theresa's parents do not want nutrition and hydration stopped, for they believe she can be rehabilitated. Theresa's parents also say that her husband wants her to die so he can inherit the remaining $700,000 of a medical malpractice judgment he won after she entered her PVS. Her husband denies this allegation and says that he has offered to give the money to charity if Theresa dies.

The dispute has engendered a great deal of media commentary for almost two years, in part because of a controversy involving the nursing home in which Theresa was a patient. The nursing home threatened to evict her because of the publicity surrounding the court case and the need for security to prevent protesters and unauthorized visitors (including Theresa's parents) from entering the building. It later, however, rescinded its threat of eviction. Nevertheless, Theresa's husband arranged for her transfer to a hospice shortly thereafter.

In late January 2001, the District Court of Appeal of Florida, Second District, affirmed a trial court's decision that Theresa's artificial nutrition and hydration be halted. The Florida Supreme Court denied review of the decision, and the United States Supreme Court refused an emergency motion to stay implementation of the order. Artificial nutrition and hydration actually was discontinued in April. Less than three days later, however, another trial judge ordered nutrition and hydration to resume after Theresa's parents filed a separate lawsuit alleging that her husband had committed perjury when he testified that Theresa had earlier said she would refuse artificial life-sustaining treatment.

As the battle rages on, the main legal issues have revolved around procedural points, such as whether appointment of a guardian ad litem to represent the patient's wishes is required (with the appellate court requiring it under these circumstances) and the type of evidence that can satisfy the applicable burden of proof (with the appellate court holding that oral statements can constitute clear and convincing evidence). The sad truth remains, however, that the legal wrangling that has accompanied this death has created a great deal of controversy at a time when all those involved should be making peace with what is apparently inevitable death.

Schiavo Case Illustrates Importance of Living Wills

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years," Schiavo said. "I'm trying to allow Terri's wishes to be followed."

For the next 60 hours, a transfixed Tampa Bay waited for her to die. Some hoped she would go quickly. Others prayed for divine intervention. One woman, a former girlfriend of Schiavo's, called a competing radio station and seemed to contradict Schiavo's on-air comments. Cindi Shook said she had dated Schiavo through the malpractice trial and, then, he said he didn't know what Terri wanted.

Terri's parents immediately sued Schiavo, alleging he had committed perjury to end Terri's life. By nightfall, their attorneys were back in a courtroom arguing that the Schindlers would suffer irreparable harm if their daughter's feedings weren't resumed until they could prove their case. Pinellas Circuit Judge Frank Quesada agreed.

As the feedings restarted, the urgency abated. But the legal skirmishes, with their charges and counter-charges, continue.

The legal battle bothers Goodman, who works with hospitals and other health practitioners to resolve end-of-life and other conflicts. The University of Miami ethicist strongly believes such decisions are best left to families, not judges. But he also thinks the courts have a fairly clear-cut ruling in the case of Schindler vs. Schiavo. Given that both sides have alleged conflicts of interest over Terri's estate, Goodman said the money "should be taken off the table" to focus on the only question that matters: What's best for Terri?

In answer, Goodman poses two more questions: "How many people, if you could take a vote, would say after 5, 7, 11 years, that what the husband is trying to accomplish is peculiar or unusual? And how many of us wouldn't want that for ourselves?"