MINUTES OF THE HOUSE COMMITTEE ON JUDICIARY

Held in Room 526, at the Statehouse at 3:30 a. m./p. m., on ~~March 19,~~, 19 79.

All members were present except:

The next meeting of the Committee will be held at 3:30 a. m./p. m., on March 20, 19 79.

se minutes of the meeting held on March 16, 19 79 were considered, corrected and approved.

JOSEPH J. HOAGLAND
Chairman

The conferees appearing before the Committee were:

Senator Winter
Dr. Robert P. Hudson, Kansas Medical Society
Representative Gillmore
Jerry Slaughter, Kansas Medical Society
Vincent DeCoursey, Kansas Catholic Conference

Vice-Chairman Stites called the meeting to order at 3:30 p.m. and introduced Senator Winter, sponsor of SB 99.

Senator Winter explained that the bill provides that the State of Kansas will allow a person who once was competent to authorize in writing, to instruct a physician to withhold or withdraw life sustaining procedures in the event of a terminal affliction. He briefly went through each section of the bill and explained it to the committee. Following several questions of committee members, Senator Winter introduced Dr. Hudson, of Kansas University Medical Center who testified in favor of SB 99. He feels this bill is very necessary since the medical profession is not now covered by this type of law.

Rep. Gillmore testified next on SB 99. He indicated he had introduced a similar bill in HB 2498 because he believes a person should have a choice in these matters and has discussed this with numerous ministers in his community and they have agreed with him. He asked the committee to consider two minor amendments to SB 99. (See Attachment # 1).

Vincent DeCoursey, Kansas Catholic Conference, testified next in opposition to SB 99. (See attachment # 2).

Following several questions by committee members, the hearing was closed on SB 99.

The meeting adjourned at 4:30 p.m.

Unless specifically noted, the individual remarks recorded herein have not been transcribed verbatim. Individual remarks as reported herein have not been submitted to the individuals appearing before the committee for editing or corrections.

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House Judiciary Committee
March 19, 1979

SB 99 - Witholding of life-sustaining procedures in certain terminal medical conditions

Proposed amendments of Kansas Medical Society

1) In New Section 4, page 3, line 108 - insert after the word "is" the following:
"reasonably believed by the physician to be"

2) In New Section 4, page 3, lines 110 and 111 - delete the following:
"of the revocation and the time, date and place, if different,"

Atch. 1

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<u>TESTIMONY</u>: Vincent DeCoursey, Executive Director
Kansas Catholic Conference

House Judiciary Committee
Re: Senate Bill 99

March 19, 1979

My name is Vincent DeCoursey, Executive Director of the Kansas Catholic Conference. I appreciate the opportunity of submitting this statement on behalf of the Conference in opposition to Senate Bill 99.

The Conference wishes first of all to express its appreciation of the motives of those who have introduced the "Living Will" proposal. We believe that it is natural and proper instinct of all caring persons that a man or woman be allowed to die a natural death and that the use of extraordinary means to artificially prolong life in terminal conditions is not a matter of obligation of reason, law or morals. Most of us either by personal experience or through tragedies of others have known the long hours, days and weeks of suffering which preceded the death of loved ones. It is therefore a natural thought to turn to an instrument such as the "Living Will" hoping to forestall that same fate befalling us or members of our families.

But what I hope to bring to this committee for its consideration are the real and potential dangers which abound in legislative intrusion into a field where first, it does not belong; second, it is not necessary; and third, which holds real danger for those whom it intends to protect.

Atch. 2

We believe such legislation to be unnecessary because:

1. Doctors and hospitals are now free to meet their responsibilities with respect to their care of the dying;

2. Patients and their families presently have the legal right to request that "extraordinary means" not be used to prolong life;

3. Fear of legal action is more imagined than real. In the history of Anglo-American jurisprudence there have been no known successful prosecutions of physician or facility based upon a failure to use "extraordinary means";

4. Legislation cannot resolve conflicts arising from questions of medical competency or the accuracy of prognosis, or that a patient's wishes be accurately interpreted.

Next we submit that the "Living Will" is undesirable and dangerous:

1. There is fear of the effect on a doctor-patient relationship. A "Living Will" statute would compel a physician to seek to conform his actions to its provisions, not necessarily to his own medical judgment.

2. There is fear of the willingness or ability of a doctor to respond to a patients needs or wishes in the absence of a signed and formal "Living Will". The rights of the patient might be seriously jeopardized if physicians, absent the security of the statute, refuse to discontinue "extraordinary means".

3. There is fear of the effects upon a patient-family relationship. It seems reasonable that some patients could be pressured into signing a living will in advance of their personal commitment to such a decision. In reverse, if there were no signed and formal "living will" would the family be compelled to conclude that the patient wishes that extraordinary means <u>not</u> be withdrawn or withheld?

4. How can any person make an intelligent decision with respect to a specific response to unknown events or circumstances.

5. There is fear of the implications relative to society itself. Legislation supposedly designed to protect rights and insure mercy can move very quickly from voluntary discontinuing of life to involuntary and direct taking of life.

In the field of legislation on "Death and Dying" Kansas was the first of the states to enact a statutory definition of death embodying the "brainwave" theory. Those who were in the legislature in 1970 remember that the basic premise on which this legislation was enacted was the necessity of protecting doctors from malpractice charges in the performance of heart transplants. It is now almost ten years since the statute was enacted and to my knowledge no heart transplant surgery has ever been performed in this state. The reason for the enactment of the statute proved to be inapplicable yet the statute remains, transferred from its original rationale into fields not even discussed at the time the legislation was considered. And I point out that Senate Bill 99 as amended by the Senate Judiciary Committee in Section 11 substantially weakens the patient's protection against being rushed into eternity to make transplantation of bodily organs more convenient.

I respectfully submit to this committee that it should not be the role of government to regulate or to interfere in every phase of human existence. All human persons have value, not because they are useful, productive, or healthy, but simply because they are human. Some in our own society are especially vulnerable to the utilitarian ethic -- the aged, disabled, retarded, mentally ill and the comatose. The government should not step further in fields best served by individual and familial relationships.

I will not attempt to discuss each section of S. B. 99. However I would call your specific attention to the broad implications of the term "life-sustaining procedures" which a physician is empowered to withhold or withdraw in treatment of persons afflicted with a terminal condition. The phrase is used in the title and in the legislative findings of new Section 1, and is defined in new Section 2(c). The problem with the phrase is that it has to be implemented by someone, and the enactment of S. B. 99 would give legal sanction to what most certainly is not the intention of those who support the bill. I call your attention to the clipping from the TRENTON, NEW JERSEY TIMES of March 5, 1979 entitled "Karen Lives". Particularly I direct your attention to paragraph 9 of column 1:

> "She is given daily injections of antibiotics to prevent infection and a high-nutrient liquid through a tube inserted in her nostrils. Some experts consider that care, no less than the respirator, to be extraordinary measures that artificially prolong her life and should be discontinued."

I ask, along with Joseph Quinlan, "How can a father not feed his daughter?" But I would further ask what "expert" would be given legal protection for his decision to starve Karen Quinlan to death?

The Karen Quinlan case has caused agonizing struggles in the minds and conscience of physicians, lawyers and theologians. The fact that she still lives creates a moral dilemma. The courts -- specifically the New Jersey Supreme Court -- decided that Joseph Quinlan could request physicians to discontinue the use of life-support machines which were then believed to keep Karen alive, because there was "no external compelling interest of the state to compel Karen to endure the unendurable". And this in the absence of a "Living Will" statute in New Jersey.

Now today we find a belief by certain "experts" that a more positive measure -- starvation -- should be used to bring about a final solution to the Karen Ann Quinlan problem; and it is our firm belief that the enactment of a "Living Will" statute is a positive step on the road to active euthanasia. I once again point out that we know and believe beyond any doubt whatsoever that such is in no way even remotely envisioned by the sponsors of the bill.

But there are others who have more "progressive" ideas.

Consider the following quotation:

> "We should increase our activities immediately and to a major degree in dealing with population control, selective abortion, problems of mentation, aging, suicide and negative euthanasia. It seems unwise to attempt to bring about major changes permitting positive euthanasia until we have made major progress in changing laws and policies pertaining to negative euthanasia."*

I rather worry about this. Here is an "expert" telling us that we "gotta go slow" in moving toward a socially engineered society which can decide who shall live and who shall die. I urge the House Education Committee to vote against Senate Bill 99.

*Robert H. Williams, M.D., Department of Medicine, University of Washington (quoted in HOSPITAL PROGRESS, February, 1977.)

KAREN LIVES ON — *She'll be 25 soon . . .and her family is at peace*

By SUSAN PAGE
Newsday

LANDINE — Joseph Quinlan visits his daughter for a few minutes each morning on his way to work, and for a bit longer each evening on his way home.

Julia Quinlan stops by the nursing home every afternoon, strokes her daughter's forehead and murmurs a brief prayer before heading home to fix dinner.

To the surprise of nearly everyone, Karen Ann Quinlan is still alive.

"The waiting we're going through right now is very difficult," Quinlan said in his quiet and matter-of-fact manner. "At least before, we were able to do something. There was medical people, different specialists we called in, always something to do."

Mrs. Quinlan added, "At least when she was in St. Clare's (hospital) and we were fighting to have the respirator removed, at least we were doing somethng active. Now it's just a matter of waiting."

IT WAS THREE years ago this month that the New Jersey Supreme Court, in a case that prompted worldwide debate, granted Quinlan's request to be declared guardian of his comatose, 22-year-old dughter. He wanted the authority to have the life-support machines disconnected from her curled and rigid body so that she could die in peace.

Finally, the machines were removed.

But her heartbeat has remained strong and she has continued to breathe, sometimes easily and sometimes with difficulty. She thrashes about occasionally. Often her blue eyes are open, though unfocused. Her weight is stable, about 70 pounds, and her gaunt body is still curled into the so-called fetal position: knees drawn up to her chest, arms folded inward.

She is given daily injections of antibiotics to prevent infection and a high-nutrient liquid through a tube inserted in her nostrils. Some experts consider that care, no less than the respirator, to be extraordinary measures that artifically prolong her life and should be discontinued.

But the family has refused. "How," Quinlan asked, "can a father not feed his daughter.?"

KAREN WILL BE 25 this.month, a birthday the family plans to celebrate with a bedside Mass at the Morris View Nursing Home and a big family dinner at the two-story, gray frame house where she was reared.

KAREN QUINLAN
. . . in 1975 photo

Karen never will recover, doctors say, but it may be years before she dies.

So her parents have managed, at last, to settle into a routine that embraces their comatose daughter as well as their other two children, their work and their church. The despair over Karen's illness and the tension of the court battle are mostly gone.

They seem at peace, and they express no regrets.

"We knew what was right, what had to be done," Quinlan said last week, sitting in the neat and modest living room, a half-dozen books about Karen on the coffee table before him. "There wasn't anything else we could do. It would have been a terrible thing, to leave someone on all that equipment, to let her spend what life she had left on that machine."

"That machine" as a Bennett MA-1 respirator, which forced air through an incision in Karen's throat and into her lungs. She had been connected to it in a hospital emergency room in the early morning hours of April 15, 1975.

THE QUINLANS, like the authorities, still do not know exactly what happened to their adopted child that night. Did the gin-and-tonics she drank, combined with the tranquilizers later found in urine and blood tests, induce her coma? How did she receive the egg-sized lump on the back of her neck and the multiple bruises on the lower part of her body?

What they do know is that she slipped into unconsciousness at a birthday party in a local tavern. Before she arrived at the hospital in a police ambulance, she had stopped breathing twice, each time for many minutes.

Although the regulators in her brain that control blood pressure and heart rate were functioning — and still are — the loss of oxygen caused the cognitive part of her brain to die.

Months passed before her parents could admit to themselves that Karen would not recover. Finally, they gave neurologist Robert Morse written permisson to disconnect the respirator, presumably allowing their daughter to die. Dr. Morse refused, citing legal and medical problems because Karen did not meet the accepted criteria of "brain death." There was still recordable brain activity, and she still had automatic reflex reactions to pain and light.

IN SEPTEMBER 1975, Quinlan filed his petition in New Jersey Superior Court. In November, his request was denied. But in March 1976, the New Jersey Supreme Court unanimously overruled the lower court, finding "no external compelling interest of the state (to) compel Karen to endure the unendurable."

Quinlan, the court ruled, should be named his daughter's guardian, and he could have the apparatus disconnected if attending physicians and a hospital ethics committee agreed that there was no reasonable possibility of her recovery.

By then, the case had raised a debate — in statehouses, courtrooms, hospitals, churches and homes — over basic issues of life and death. The Quinlan case, establishing legal precedents and promoting legislation, has become a symbol of the right of terminal patients and their families to refuse modern medical treatments that prolong life.

"I think she symbolizes the right to live — I hate the phrase 'right to die' — in comfort and peace until the Lord calls her," Mrs. Quinlan said. "We have never asked for Karen's right to die, only for the right to remove extraordinary medical equipment, and those are very different things in our minds.

"Although," she added, "we certainly never expected her to live this long."

THE ONLY PERSON who had raised the possibility during the court case that Karen might survive was Dr. Julius Korein, a professor of neurology at the New York University Medical Center, who was the family's expert witness at the trial. He told the Quinlans and the court that without the respirator, Karen might die immediately or might live for years.

"We're not dealing with brain death," Dr. Korein said last week. "We're dealing with a persistent vegetative state. In such situations, an individual may go on as much as 10 or 20 years, if you support them with medical care."

In June 1977, Karen caught pneumonia, and the family and the doctors agreed not to increase Karen's anbibiotic injections to fight the infection. The Quinlans' priest, the Rev. Thomas Patrasso, administered last rites. "We let nature take its course," Mrs. Quinlan said, "and she lived."

JOSEPH QUINLAN is 53 now. In the past four years, he has put a bit of weight on his solid 5-foot, 9-inch frame and his hair has become grayer. He has filled one large scrapbook with newspaper clippings about Karen — labeled in gold with the title of the case, "In the Matter of Karen Ann Quinlan" — and has started a second one. He has decided there must be a reason for his ordeal and a purpose in his daughter's suffering.

"I think God is using Karen," Quinlan said. "He has reached, between using Karen and the news media, millions of people on this earth and spread his love and peace. Karen has a lot of people praying for her.

"That's a pretty good sign God is using her for some reason," he said. "We keep searching for it."

JULIAN QUINLAN, now 52, is a petite woman with direct brown eyes and a straight forward manner. She said she thinks God's purpose might be the establishment of a hospice to help terminally ill patients and their families. The Quinlans have donated proceeds from a book and a movie about Karen to help establish a hospice program in her memory in the community.

"People who are dying somehow live until their work is completed on earth," Mrs. Quinlan said. "I think when Karen's work is completed, God will take her home."

Meanwhile, Karen lies on a water bed in the sunny second-floor room, which is sealed by a special electric lock to forestall intruders. A crucifix is over her bed and religious pictures are on the cream-colored walls. The nurses keep the bedside radio tuned in to a rock-music station, and they talk to her as they change her body position every two hours to prevent bed sores. They know she cannot hear, but it helps preserve her humanity for them.

QUINLAN STILL works as a section foreman at the Warner-Chilcott Laboratories. Mrs. Quinlan still works as a secretary for her parish, Our Lady of the Lake. Their 22-year-old daughter, Mary Ellen, is a senior at Centenary College in Hackettstown. Their 21-year-old son, John, is a student at Cochise Community College in Douglas, Ariz.

They have resumed the daily routine of their lives, and they have prepared for Karen's death. A family plot has been purchased at the Gate of Heaven Cemetery in Hanover. In a file at the parish rectory are plans for her funeral Mass, to be held in the small Catholic church where she was baptized and confirmed.

When Karen's health begins to fail, when the breathing falters or when a serious infection begins, no heroic measures will be taken to save her, the family and the nursing home officials have agreed. When Karen dies, administrator Fred Swanson said, "a public announcement will be made, involving the family."

"They do it when kings die, and queens," Swanson said, "and we'll do it for Karen."