Approved: 3-9-07
Date

MINUTES OF THE HOUSE JUDICIARY COMMITTEE

The meeting was called to order by Chairman Mike O'Neal at 3:30 P.M. on February 7, 2007 in Room 313-S of the Capitol.

All members were present.

Committee staff present:
Jerry Ann Donaldson, Kansas Legislative Research
Athena Andaya, Kansas Legislative Research
Jill Wolters, Office of Revisor of Statutes
Duston Slinkard, Office of Revisor of Statutes
Cindy O'Neal, Committee Assistant

Conferees appearing before the committee:
Shawn Kane, American Adoptions
Mike Belfonte, Adoption Attorney
Austin Vincent, Adoption Attorney
Representative Lance Kinzer
Kathy Ostrowski, Kansans for Life
Rocky Nichols, Disability Rights Center of Kansas
Tammy Coleman, Individual from Raytown, Mo
John Carney, Life Project

The hearing on **HB 2186 - restrictions on advertising for adoption and child placement agencies**, was opened.

Shawn Kane, American Adoptions, appeared before the committee as a proponent of the bill. He stated that 17 states have passed adoption laws that are similar to those being proposed today. The law would require anyone who advertises to provide adoptions to be licensed in Kansas and to have their licensed number listed in their ad. (Attachment 1)

Mike Belfonte, Adoption Attorney, appeared in support of the proposed bill and asked for an amendment that bill not apply to licensed child placement agencies that are in operation and authorized by Kansas law. (Attachment 2)

Austin Vincent, Adoption Attorney, appeared in opposition to the proposed bill because it does not address the problem with the statute and expand it to include "licensed child placement agencies." (Attachment 3)

The hearing on **HB 2186** was closed.

The hearing on **HB 2176 - wards and guardians; duties and powers of guardians concerning the withholding of nutrition and hydration**, was opened.

Representative Lance Kinzer appeared as the sponsor of the proposed bill and stated that authority of guardians over wards has never been viewed as absolute and is always subject to court oversight. Current law also has the presumption that guardians do not have the authority to consent on behalf of wards, to withdraw life saving or life sustaining medical care. There are two exceptions to this rule:

- when a ward has executed an advance directive setting forth his wishes
- when a guardian withholds nutrition and/or hydration

The proposed bill addresses the second exception by requiring before medical treatment could be removed the ward must be "comatose and suffering from a sever illness such that life sustaining medical care is objectively futile and would only prolong the dying process." It would also create a presumption in favor of continued medical care in the absence of evidence of contrary intent by the ward and providing food and hydration would be viewed as a natural means of preserving life rather than as a medical act. (Attachment 4)

Kathy Ostrowski, Kansans for Life, was in support of the proposed bill but requested an amendment to

remover the word "comatose" and the following language regarding imminent death: "The ward is suffering from a sever illness such that life sustaining medical care is objectively futile because death is imminent and such provision would only prolong the dying process. (Attachment 5)

Rocky Nichols, Disability Rights Center of Kansas, appeared as a proponent of the bill which fixes three flaws in current law:

1. The definition of who can have medical care withheld or withdrawn
2. Lack of due process rights of the individual with a disability affected by the guardian's petition and court action
3. The lack of discretion by the current statute.

Mr. Nichols proposed two amendments; on page two, line 1, change the word "may" to "shall". This will afford the ward full due process with the proceedings involving nutrition and hydration. The second amendment would be to delete Section 1(g) because it allows for violation of a person with a disabilities' rights if no one objects. (Attachment 6)

Tammy Coleman, Individual from Raytown, Missouri, relayed her story of being in a car wreck and spending time in a hospital & nursing home. (Attachment 7)

John Carney, Life Project, requested that the committee not take any action on the proposed bill until the Kansas Judicial Council has issued its report on End of Life issues. (Attachment 8)

Written testimony, in opposition to the bill, was provided by Hospice Services, Inc. (Attachment 9)

The hearing on **HB 2176** was closed.

The committee meeting adjourned at 5:25 p.m. The next meeting was scheduled for February 8, 2007.

AMERICAN ADOPTIONS
1-800-ADOPTION
www.americanadoptions.com

Outline of the American Adoptions presentation of House Bill No. 2186

Why are we here today talking about an adoption advertising statue?

- Experience of Kansas (KS) licensed professionals
- Lack of services
- Laws
- The residence of KS

What does this mean exactly?

- An Adoption Facilitator is unlicensed organizations or individuals offering adoption services.
- Lack of standards
- 17 states
- Oklahoma
- Other examples are out of state agencies and attorney's
- Position left for KS attorney's, KS judges and KS agencies

Who?

- Facilitators (typically on the west coast)
- Out of State attorneys (typically from the east and west coast)
- Out of State licensed agencies (typically from the east or west coast)
- Prospective Adoptive Couples from all over the country

Where?

- Sample study conducted by American Adoptions of South Western Bell and Yellow book of Adoption listing.
- Hundreds of phone books in the state of KS
- 40
- Sample 1 and 2
- Kaw Valley Center
- Example

How can the state of Kansas get involved?

The current bill in place has great intentions, but needs to be cleaned up and stiffer penalties added to prevent outside professionals from advertising in the state of Kansas.

House Judiciary
Date 2-7-07
Attachment # 1

9101 W. 110th Street Suite 200 Overland Park, KS 66210
1-800-ADOPTION (236-7846) adoptions@americanadoptions.com 913-383-1615 Fax

Mike Belfonte

HOUSE BILL NO. 2186

(b) The provisions of subsection (a) (1) shall not apply to ~~a licensed child placement agency operating as authorized by Kansas law or to~~ the department of social and rehabilitation services or to an individual seeking to adopt a child.

House Judiciary
Date 2-7-07
Attachment # 2

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June 1, 1993

ATTORNEY GENERAL OPINION NO. **93-70**

The Honorable Mark Parkinson
State Senator, Twenty-Third District
15587 S. Greenwood
Olathe, Kansas 66062

Re: Probate Code--Adoption--Advertising Restrictions

Synopsis: K.S.A. 1992 Supp. 59-2123(a)(1) which prohibits advertisements relating to adoptions violates the first amendment to the United States constitution. Cited herein: K.S.A. 1992 Supp. 59-2112; 59-2123; 59-2130; 59-2132.

* * *

Dear Senator Parkinson:

You request an opinion concerning whether K.S.A. 1992 Supp. 59-2123(a)(1) which prohibits a person, other than a licensed child placement agency or the department of social and rehabilitation services, from advertising for adoption violates the first amendment to the United States constitution.

K.S.A. 1992 Supp. 59-2123 provides, in relevant part, as follows:

"(a) Except as otherwise provided in this section:

"(1) No person shall advertise that such person will adopt, find an adoptive home for a child or otherwise place a child for adoption;

. . . .

"(b) The provisions of subsection (a)(1) shall not apply to a licensed child placement agency operating as authorized by Kansas law or to the department of social and rehabilitation services.

"(c) As used in this section:

"(1) 'Advertise' means to communicate by newspaper, radio, television, handbills, placards or other print, broadcast or electronic medium;

"(2) 'person' means an individual, firm, partnership, corporation, joint

2-2

venture or other association or entity. . . ."

The Kansas adoption and relinquishment act addresses both independent adoptions and agency adoptions. K.S.A. 1992 Supp. 59-2112. An independent adoption occurs when the child's birth parent or some nonagency person *in loco parentis* consents to an adoption. An independent adoption does not require the services of a licensed agency to serve as an intermediary between the birth and adoptive parents. An agency adoption occurs when an entity licensed by the state is authorized to place children for adoption and can consent to the adoption. K.S.A. 1992 Supp. 59-2112(f). The licensed agency is the intermediary between the birth and the adoptive parents. Both types of adoption require investigation and a report to the court concerning the petitioner's ability to care for the child as well as background information on the child and the birth parent(s). K.S.A. 1992 Supp. 59-2130 and 59-2132.

In 1986 nearly one-third of all states, including Kansas, had express limitations on adoption advertising in order to curb black-market activities involving the payment of large fees by hopeful adoptive parents to unscrupulous intermediaries and questionable child placements. *Comment, Advertising for Adoption Placement*, 25 Duquesne L.Rev. 129, 132, 140 (1986). The purpose of the advertisement restriction in K.S.A. 1992 Supp. 59-2123 is to discourage marketing of children across state lines and circumventing the laws of states where non-agency adoptions are not legal. *Minutes* , House Committee on Public Health and Welfare, January 31, 1984, attachment 3. Dr. Robert Harder, the secretary of the department of social and rehabilitations services, testified that the majority of advertisements were placed by individuals from out of state who were seeking prospective birth parents. *Minutes*, House Committee on Public Health and Welfare, January 31, 1984, attachment 3.

With this background in mind, we consider whether the advertisement prohibition violates the first amendment to the United States constitution as applied to the states through the fourteenth amendment. The first amendment prohibits abridging the freedom of speech, however, "commercial speech" which is defined as expression relating solely to the economic interest of the speaker and its audience is not as highly protected as other forms of speech. *Central Hudson Gas and Electric Cooperation v. Public Service Commission*, 447 U.S. 557, 100 S.Ct. 2343, 65 L.Ed.2d 341 (1980), *Robert Rieke Bldg. Co. v. City of Overland Park*, 232 Kan. 634 (1983). Advertising in connection with adoptions is "commercial speech." *Adoption Hotline Inc. v. State*, 402 So.2d 1307 (Fla. Dist.Ct.App. 1981). However, because society has a strong interest in the free flow of commercial information, a state may not completely suppress the dissemination of truthful information about lawful activities. *Virginia State Board of Pharmacy v. Virginia Citizens Consumer Council*, 425 U.S. 748, 96 S.Ct. 1817, 48 L.Ed.2d 346 (1976). Commercial expression not only serves the economic interest of the speaker but also assists consumers and furthers the societal interest in the fullest possible dissemination of information. *Central Hudson*.

The validity of a restriction on commercial speech is measured by a test stated in *Central Hudson*. In order for commercial speech to be protected under the first amendment it must concern lawful activity and not be misleading. The next question is whether the asserted governmental interest is substantial. If both inquiries are answered affirmatively, the court must determine whether the regulation directly advances the government interest asserted and whether it is not more extensive than

is necessary to serve that interest. Restrictions must directly advance the state interest and if the government interest could be served as well by a more limited restriction on commercial speech, any excess restriction will fail. *Central Hudson*. There has to be a "fit" between legislative ends and the means chosen to accomplish those ends - a fit that is not necessarily perfect, but reasonable. *Board of Trustees, S.U.N.Y. v. Fox*, 492 U.S. 469, 109 S.Ct. 3028, 106 L.Ed.2d 388 (1989).

In *Adoption Hotline*, the court concluded that a permanent injunction against all advertising by an unlicensed adoption placement referral service was too broad and, therefore, was an impermissible violation of the first amendment. Without a showing by the state that a narrower restriction would be insufficient to protect the government's interest or that the advertisement was misleading, a complete prohibition was unconstitutional. Following the reasoning in the *Adoption Hotline* case and applying the *Central Hudson* test to K.S.A. 1992 Supp. 59-2123(a)(1), it is our opinion that the prohibition violates the first amendment because it is too broad to advance the asserted state's interest. There is no doubt that the state has a substantial interest in the welfare of Kansas children and insuring that their placement with adoptive parents is in their best interest as well as preventing any profiteering in this area. However, independent adoptions are legal in this state and, assuming that the advertisement is not misleading, the complete prohibition of all advertising (except for certain entities) is too broad to accomplish the state's purpose. While the intent of the statute was to prevent out of state persons from placing advertisements, the prohibition also applies to Kansas attorneys or Kansas adoptive parents seeking to find Kansas birth mothers who may be interested in giving up their children for adoption. In short, the prohibition cuts too wide a swath and thwarts the societal interest in the dissemination of information which the first amendment was designed to protect. *Central Hudson*. (We offer no opinion concerning whether the legislature could prohibit advertising solely from persons out of state. We also do not here address advertising for surrogate mothers.)

The state may always ban communication which is more likely to deceive the public than to inform it. *Ohralik v. Ohio State Bar Association*, 436 U.S. 447, 98 S.Ct. 1917, 56 L.Ed.2d 444 (1978). However, if the advertisement is not misleading, the state cannot impose a total prohibition on persons who are desirous of finding birth mothers interested in giving up their children for adoption. Consequently, it is our opinion that K.S.A. 1992 Supp. 59-2123(a)(1) violates the first amendment to the United States constitution.

Very truly yours,

ROBERT T. STEPHAN
Attorney General of Kansas

Mary Feighny
Assistant Attorney General

RTS:JLM:MF:jm

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TESTIMONY IN OPPOSITION TO HB 2186
BEFORE THE HOUSE JUDICIARY COMMITTEE ON FEBRUARY 7, 2007

Subsection a (1) ADVERTISING TO ADOPT:

Attorney General Opinion 93-70: *"There is no doubt that the state has a substantial interest in the welfare of Kansas children and insuring that their placement with adoptive parents is in their best interests as well as preventing any profiteering in this area. However, independent adoptions are legal in this state and,* ***assuming the advertisement is not misleading, the complete prohibition of all advertising (except for certain entities) is too broad to accomplish the state's purpose.*** *While the intent of the statute (59-2123) was to prevent out of state persons from placing advertisements, the prohibition also applies to Kansas attorneys or Kansas adoptive parents seeking to find Kansas birth mothers who may be interested in giving up their children for adoption. In short, the prohibition cuts too wide a swath and thwarts the societal interest in the dissemination of information which the first amendment was designed to protect."*

HB 2186 in no way addresses the original problem with the statute, except to add more confusion. 2128 simply expands the exception for "licensed child placement agency" to "persons licensed by the State of Kansas in such person's profession." Therefore, the amended statute would remain a "complete prohibition of all advertising, except for certain entities."

Subsection a (3) OFFERS TO ADOPT:

The original statute and the proposal sanction the free exchange of information among those who most need to communicate in order to accomplish a desired goal.

What evil do we seek to eradicate? I suggest you repeal the present unenforceable statute and explore KSA 59-2121 as an avenue to address the real problem.

Respectfully,

Austin K. Vincent

House Judiciary
Date 2-7-07
Attachment # 3

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STATE OF KANSAS
HOUSE OF REPRESENTATIVES

TOPEKA

LANCE KINZER
REPRESENTATIVE, 14TH DISTRICT

COMMITTEE ASSIGNMENTS
TAXATION
JUDICIARY
FEDERAL AND STATE AFFAIRS

TESTIMONY REGARDING HB2176

"... we must be wary of those who are too willing to end the lives of the elderly and the ill. If we ever decide that a poor quality of life justifies ending that life, we have taken a step down a slippery slope that places all of us in danger. " -- C. Everett Koop, M.D.

Thank you for this opportunity to address HB 2176 regarding end of life decisions under the Guardianship Act. It is important to start by stressing that this legislation applies only to situations where a court appointed guardian is already in place; in other words to cases where a court is already involved in the life of the ward whose medical condition is in question. Under current law guardians are empowered to make a large number of decisions for wards with very little outside interference. However, there are nine categories of decisions over which guardians have limited or no authority to make decisions for their wards (see Section 3 (e)). These include the fact that **under current law a guardian can not** prohibit the wards marriage, consent to the termination of the wards parental rights, consent to adoption of the ward without court approval, consent to any organ donation by the ward without court approval, consent to sterilization of the ward without court approval, exercise authority of the wards estate without court approval and a few other items as well. The point is that the authority of guardians over wards has never been viewed as absolute and is always subject court oversight.

One further area in which we do not allow guardians' unfettered authority is in the area of end of life decisions. Indeed, **current law begins with the presumption that guardians do not have the authority to consent on behalf of wards, to the withdrawal of life-saving or life sustaining medical care.** There are two basic exceptions to this rule; the first is where the ward has executed an advance directive setting forth his or her wishes in this regard. The second is the situation that is addressed by HB 2176.

In particular, current law says that life sustaining medical care can be withdrawn where the wards doctor, plus one other doctor, confirm that the ward is either in a persistent vegetative state or "is suffering from an illness or other medical condition for which further treatment, other than for relief of pain, would not likely prolong the life of the ward other than by artificial means, nor would be likely to restore to the ward any significant degree of capabilities beyond those the ward currently possesses." I want to stop and consider this language because it one of what I believe to be several problems with the existing statute. **The current definition is overly broad in that it could apply to highly functioning people who need some artificial means (like a portable respirator) to sustain life.** Many within the disability rights community have expressed real concern that this language opens the door to mischief. Secondly, the use of the term vegetative is offensive to some.

My proposal would involve deleting the language quoted above, replacing it with a requirement that before medical treatment could be removed the ward must be "comatose and suffering from a severe illness such that life sustaining medical care is objectively futile and would only prolong the dying process." The term comatose means a state of profound unconsciousness from which one can not be roused. The remainder of the proposed language is designed to ensure that in the

denial of medical care we are giving due attention to the distinction between allowing nature to take its course and actively assisting death.

Under current law once a decision is made by the doctors that the ward meets the statutory definition for withdrawal of medical care the guardian provides their written certification to the court. **The law states that "Such written certification shall be approved by an order issued by the court."** Two points are crucial to consider in this regard, first the existing statute requires judicial involvement in the end of life decision of a guardian for a ward. But second, the current language directing that involvement is confusing. **The use of the term "shall" in the current law appears to suggest that the Judge has no choice but to sign the withdrawal order.** The Judicial Council committee on which I serve heard testimony on this issue and it was my impression from that testimony that Judges themselves take a range of opinions on the meaning of the current statute. Wherever one stands on this issue I think we can all agree that the nature and extent of the review to be conducted by the court should not depend upon which judicial district you live in. **We need to clarify this portion of the statue and guarantee that wards receive a meaningful due process hearing prior to withdrawal of life sustaining medical care.**

My proposal would require that the court conduct a two part inquiry. First the court would consider evidence as to whether or not the ward is actually in the medical condition specified by the statute. Second, and this is a significant change, the court would consider whether the ward ever expressed consent to the withdrawal of medical care. **My proposal would create a presumption in favor of continued medical care in the absence of evidence of contrary intent by the ward; current law gives no consideration to the wards intent under these circumstances.**

Finally, my proposal would establish a separate standard for the withdrawal of nutrition and hydration. **In particular, providing food and hydration would be viewed as a natural means of preserving life rather than as a medical act. As such they could be withdrawn only if it were not medically possible to provide them without harming the ward, or where the ward has signed a proper advance directive on this issue.** Where an advance directive is in place no prior court action would be required for withdrawal, but legal standing would be given to interested parties to initiate such action if their was a concern of possible abuse of this process.

This distinction between nutrition and hydration and medical care is based upon the belief that nutrition and hydration are, in principle, ordinary and proportionate, and as such morally obligatory.

Nutrition and hydration are different from medial care such as respirators for the simple reason that death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission to deny a person food and water. In other words the withdrawal of nutrition and hydration are actions by the very nature of which bring about death.

Furthermore, we must not underestimate the fact that provision of food and water are powerful symbols of care and comfort that acknowledge the inherent value we see in all human begins. **To deny food and water to a fellow human being is to place in question their status of a member of the community for whom we have a duty to act in accordance with the basic demands of human dignity.**

To deny nutrition and hydration as a result of arbitrary considerations regarding an individuals "quality of life", is to risk allowing psychological, social and economic pressures, to take precedence over our obligations to fellow human begins; even fellow human beings who are weak.

No cost benefit analysis can outweigh the fundamental value of human life. To determine that decisions regarding human life can be based upon an external analysis of its quality, introduces a discriminatory and eugenic principle into our social relations.

HB 2849 is ultimately about human dignity and our societal obligations to the weakest among us. Those who are wards are, even under the best of circumstances, persons who lack the capacity to meet their own needs in some respect. Wards in end of life circumstances are particularly vulnerable and deserving of special care. Such persons should be protected by laws that ensure adequate due process and that acknowledge their essential human dignity.

I appreciate the opportunity to address this important issue and look forward to answering any questions you may have.

Kansans for Life

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PROPONENT – HB 2176

House Judiciary Committee

Feb.7, 2007

Good afternoon, Chairman O'Neal and members of this Committee. I am Kathy Ostrowski, Legislative Director for Kansans for Life, an affiliate of the National Right to Life Committee. Our concern is protection of innocent human lives, particularly those threatened by abortion, infanticide and euthanasia.

I am here today in support of House Bill 2176, a proposal to protect Kansans with disabilities. Our focus in this legislation is to correct Kansas law in favor of a presumption ***for*** life, when a ward of the state has ***not*** executed an informed and express document against certain end-of-life measures.

There is an understandable reluctance to take ordinary matters to court. But we are not dealing with ***ordinary*** matters here, and the law would ***not*** be imposing new duties to families at the bedside.

Current Kansas law does not afford due process rights for people with disabilities before medical care, including food and water, can be withheld or withdrawn. In fact, current law ties the judge's hands; directing a judge to allow the ward to lose his life if the guardian files such a petition attesting to the ward's precarious medical condition. The petition would have to be signed by 2 doctors or one doctor and a hospital review board.

Unfortunately, hospital review panels' decisions, and physicians' advice, can represent a quality of life decision that overshadows a medical analysis. See Attachment A-- a sample of studies in which patients rated their quality of life as high, but their physicians rated the same patients as having a low quality of life. And while the guardian is supposed to be selected carefully, overtime, human nature being what it is, the guardian's view of the ward's quality of life may deteriorate more than the ward's health does.

In consultation with health and legal experts, we would offer a suggestion to improve HB 2176. At section e (7) (c) on page 8, we would delete "comatose and "and add the following words concerning imminent death to read:

> *[The ward is] suffering from a severe illness such that life sustaining medical care is objectively futile because death is imminent and such provision would only prolong the dying process,*

As a medical term, "comatose" is arguably still imprecise. A coma, or loss of consciousness, can be induced by medication as well as being the product of underlying medical problems, such as kidney failure, brain injury, etc. It should be sufficient to allow the competent physician to assess the existence of a severe illness --with death as imminent—to cover the intended medical scenarios of the existing statute.

As an aside, comas are not alike and not all outcomes are reasonably predictable: pregnant women in comas have given birth, some persons with minimal consciousness have recovered after years, and recently, some were "awakened" when given the sleeping pill 'Ambien". See Attachment B.

In conclusion, it is the grave responsibility of this committee to structure the law to protect the lives of Kansans who may not possess a worthy guardian at the time their lives are in jeopardy. Certainly, the high-profile convictions of the Kaufmans are instructive. They were viewed as pillars of the community, while behind closed doors they were inflicting horrific sexual, mental and physical abuse on disabled Kansans for over 20 years.

HB 2176 can correct Kansas' current fatally flawed law that denies due process to the ward and allows no discretion to the court. Even convicted criminals are afforded due process before the death sentence is carried out -- Kansans with disabilities deserve no less.

Thank you, I stand for questions.

House Judiciary
Date 2-7-07
Attachment # 5

How good are doctors at diagnosing DNR patients' quality of life?

Noelle Junod Perron, Alfredo Morabia, Antoine de Totrente -Switzerland
http://www.smw.ch/pdf200x/2002/39/smw-10083.PDF

This 2002 study assessed quality of life evaluation on the implementation of Do-Not-Resuscitate (DNR) orders by physicians and the accuracy of physicians' estimation of DNR patients' quality of life
Methods: A 10-month prospective clinical study in a community hospital including 255 DNR patients and 9 physicians in postgraduate training.

In many fields of medicine **quality of life is becoming a common item in the assessment** of outcome and health status. Furthermore, it is often used as a criterion for the appropriateness of intervention or treatment in clinical situations. Thus, it is of considerable importance to know to what extent physicians are able to estimate their patients' quality of life. However, physicians underestimated quality of life components of DNR patients.

Conclusion: **Physicians often (71 %) rely on the assumed quality of life of their patients in their DNR decision but unfortunately tend to underestimate it.** Greater involvement of patients in the DNR decision could improve quality of care.

The "misery" perspective: patients more positive than providers

Cheryl Lapp *http://www.uwopartners.org/whatsnews/fall2000/healthview.html*
It has long been noted in professional literature that there is a distinct gap between self-assessed health on the part of older adults and health ratings assigned to them by professional clinicians. Older adults' assessments of their own health are considered to be valid indicators, but interestingly, their health ratings are consistently more positive than the ones presented by professionals.

This 2000 study conducted in the Oshkosh area explored differences in health perceptions, utilizing a sample of 30 **older women, each paired with her own primary health care provider**. The average age of the sample was 83 years, whereas the providers' average age was 48 years, over three decades younger than the subject sample. Most of the women in this semi-rural community had long-standing relationships with their providers, typically ten to fifteen years in duration.

Based on the 60 in-person interviews, paired data were analyzed and compared. In these stable relationships, the health ratings of the patient/provider pairs actually matched 43% of the time. When they **did not match in another 40% of pairs, the older adults' ratings were more positive, a result consistent with the literature.**

Depressed mood in spinal cord injured patients: staff perceptions

Cushman LA, Dijkers MP. University of Rochester School of Medicine and Dentistry, NY.
Arch Phys Med Rehabil. 1990 Mar;71(3):191-6.

This 1990 study examined the correspondence between staff ratings and patient ratings of depressed mood for 102 newly spinal cord injured persons admitted to two regional spinal cord injury rehabilitation centers. Patients rated their mood by using the Depression Adjective Check List (DACL). Treatment staff also rated each patient by completing the DACL as they thought the patient would have on the same day. Ratings were made every three weeks during a patient's stay.

Results: **Staff members typically overestimated levels of patients' depressed moods.** Staff's accuracy in estimating patient mood did not increase with increased exposure to the patient or years of experience in rehabilitation.

Boy in "hopeless" vegetative state awakens, steadily improves

By Hilary White October 10, 2006 *http://www.lifesite.net/ldn/2006/oct/06101001.html*

GRESHAM, Oregon October 10, 2006 (LifeSiteNews.com) – A young boy, who had previously been diagnosed as being in a "persistent vegetative state," has awakened from a 22 month-long coma and is breathing on his own. Devon Rivers collapsed in a seizure during a phys-ed class in 2004 and his condition was never explained, though some doctors suggested it was caused by an unknown viral infection. **Doctors agreed, however, that he had little hope of recovery.** His mother, Carla Rivers, visited him regularly and, in addition to physical therapy by his paediatric nursing home to keep his limbs supple, she talked to him in the belief that coma patients can retain their hearing and some understanding (S)ome doctors and ethicists are questioning the accuracy of the diagnosis of "persistent vegetative state" (PVS). The diagnosis is ambiguous in that symptoms of patients can vary greatly and still be called "vegetative." A 1996 study published in the British Medical Journal showed that **43% of patients diagnosed with PVS do not qualify for the diagnosis.**In 2003, Kate Adamson, a former coma patient who had been diagnosed PVS, appeared on the television talk show the O'Reilly Factor. She said that, like Terri Schiavo, the hospital had removed her feeding tube that was only reinserted after eight days when her lawyer-husband threatened to sue the hospital.

Woman in coma gives birth to full-term baby

Lisa Cornwell **Chicago Sun-Times Jul 27, 2001**

CINCINNATI--A car crash victim who was in a coma virtually her entire pregnancy has given birth to a healthy, nearly 8-pound daughter. Doctors said it is one of few known cases in the United States in which a comatose woman was able to carry a baby to **full term.**

Coma woman gives birth to twins **Independent, The (London), Jul 9, 1999**

A MONTH after a Californian, Maria Lopez, 25, slipped into a coma, she awoke and gave birth to **twins**. She is conscious and recovering and her babies are healthy. In April Mrs Lopez began complaining of headaches, which doctors blamed on her pregnancy.

Raped coma victim gives birth **AP Published: March 19, 1996**

A woman who was raped while in a coma in a nursing home gave birth today, nine weeks prematurely, to a 2-pound, 11-ounce boy. The son was doing well and the mother appeared to be in good physical condition, hospital officials said. The 29-year-old woman, who has been in a coma since an automobile accident 10 years ago, gave birth at Strong Memorial Hospital here. Her pregnancy was first noticed in late December by staff members who took care of her at a suburban Rochester nursing home. Doctors said they believe it is the **first documented case of someone becoming pregnant and giving birth while in a chronic coma.**

Sleeping Pill awakens "PVS" Patients

From Physicians for Life, August 2006 *http://www.physiciansforlife.org/content/view/1132/33/*

SLEEPING PILL AWAKENS "PVS" PATIENTS. As reported earlier, a South African man thought to be in PVS for 3 years, was prescribed a sleeping pill to calm him down. Within 25 minutes of receiving the pill, the man awoke and began talking. Louis' case was one of 3 such cases reported in the May 2006 issue of the medical journal *NeuroRehabilitation*. All 3 cases involved males around age 30 who **had been in "PVS" at least 3 years.** All were given daily doses of Zolpidem (brand name Ambien) twice each day, to keep them conscious for about 8 hours. Their responses were monitored for 3-6 years. Researchers found no long-term side effects and concluded, "Zolpidem appears an effective drug to restore brain function to some patients in the PVS'. The Glasgow Coma Scale and Rancho Los Amigos Cognitive test scores for all 3 men improved with the drug's use. South African physician Dr. Nel [co-author of the study]: "There is a lot of research to be done before we can start using this drug on others, but now we have something we can work on...**When you think about how many life-support machines have been switched off over the years, it makes you wonder."** [NeuroRehabilitation, 31May06, pp 23-28; UPI, 1June06; ITF Update, 2006, vol. 20, no. 3]

DISABILITY RIGHTS CENTER of KANSAS
EQUALITY • LAW • JUSTICE

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Testimony to the House Committee on the Judiciary

Testimony in Support of HB 2176; February 7, 2007

Chairman O'Neal and the honorable members of the committee, my name is Rocky Nichols. I am the Executive Director of the Disability Rights Center of Kansas, formerly Kansas Advocacy and Protective Services (KAPS). The Disability Rights Center of Kansas (DRC) is a public interest legal advocacy agency, part of a national network of federally mandated and funded organizations legally empowered to advocate for Kansans with disabilities. As such, DRC is the officially designated protection and advocacy system for Kansans with disabilities. DRC is a private, 501(c)(3) nonprofit corporation, organizationally independent of both state government and disability service providers. As the federally designated protection and advocacy system for Kansans with disabilities our task is to advocate for the legal and civil rights of persons with disabilities as promised by federal, state and local laws, including representing persons with disabilities to ensure their right to due process of law.

The way that Guardians make life and death decisions on behalf of their ward is an uncomfortable and sometimes controversial discussion. However, because of the fatal flaws inherent in the current Kansas guardianship statute that must be addressed, the DRC and others proposed HB 2307 in 2004. Since that time new language has been developed.

Today we testify in support HB 2176 because it is a substantial improvement to current Guardianship law in K.S.A. 59-3075(e)(7)(C). HB 2176 creates new law for the withholding of food and water and also incorporates many of DRC's previous suggestions to help fix the fatal flaws in Kansas Guardianship law. Though we support the bill, you will find at the end of my testimony suggested changes to improve HB 2176.

The Supreme Court has handed down many decisions involving the due process rights of murderers who have been given the death penalty. These cases they have reinforc

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who is subject to a death sentence must be afforded full and complete due process. Surely we can agree that in situations where death is the result (like when medical care – including food & water – are withheld or withdrawn), persons with disabilities in need of a guardian deserve no less due process protections than the person convicted of a capital crime.

Let me be absolutely clear, in situations where there the person with the disability has executed a durable power of attorney for health care decisions (DPOA), a living will or other form of written advance directives regarding end of life decisions the requirements of K.S.A. 59-3075 (e)(7)(C) do not apply. K.S.A. 59-3075 (e)(7)(C) also does not apply in situations when there is not a court appointed guardian.

Historical Background

Guardianship law in Kansas was substantially unchanged from 1965 until 2002. In 1997, the Kansas Judicial Council advisory committee on guardianship and conservatorship started to review and draft an entire new code. The advisory committee's proposal was adopted by the Judicial Council and introduced in 2001 in the House Judiciary Committee as HB 2469. The bill was over 110 pages long. There were many opponents to the bill, including the Disability Rights Center of Kansas, then known as Kansas Advocacy & Protective Services. The bill was referred for an interim study. No changes were proposed by the interim committee. The Judicial Council proposed some changes. The withhold / withdraw provisions in HB 2469 went through multiple variations during the process. For example, at times HB 2469 included due process rights and of course in the final version those rights were withdrawn. Once again, even though everyone agreed that overall the changes were positive, many opponents testified. After much debate, all the parties agreed that it was better to have the bill pass in that session and for advocates and other interested parties to come back with changes individually in succeeding years.

Fixing the Fatal Flaws in Withholding or Withdrawing Medical Care

HB 2176 eliminates the three fatal flaws in current state law: 1) The DEFINITION of who can have medical care withheld or withdrawn; 2) The lack of DUE PROCESS RIGHTS of the individual with a disability affected by the guardian's petition and court action; 3) The lack of DISCRETION by the current as directed in the current statute.

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DEFINITION FIX: K.S.A. 59-3075 (e)(7)(C) has a definition problem that puts at risk all wards who have disabilities who are "in a persistent vegetative state **or** is suffering from an illness or other medical condition for which further treatment, other than for the relief of pain, would not likely prolong the life of the ward other than by artificial means, nor would be likely to restore to the ward any significant degree of capabilities beyond those the ward currently possesses." This very broad definition can basically include any person with a disability who uses on any type of "artificial means" for day to day living (many people with disabilities use artificial means and without these artificial means there life would not be prolonged).

For example, an individual who experiences a cervical spine injury in vertebras 1, 2 or three may require artificial respiration to breathe. Or, a person with advanced kidney disease might require kidney dialysis. Some Kansans with disabilities use an iron lung during part of the day to breath. Many Kansans with significant disabilities utilize feeding tubes to eat in order to get for nutrition. None of these conditions by themselves are an indication that the person is terminally ill, or waiting on deaths door. However, as it is currently enacted K.S.A. 59-3075 (e)(7)(C) applies to the examples of individuals I just gave. DRC does not believe that the legislature intended that consequence when they revised the guardianship statute in 2002, but it is the current reality.

DRC supports the new definition proposed in HB 2176 that changes the law to read, ". . . the ward is comatose and suffering from a severe illness such that life sustaining medical care is objectively futile and would only prolong the dying process, and which opinion is concurred in by either a second physician or by any medical ethics or similar committee to which the health care provider has access established for the purposes of reviewing such circumstances and the appropriateness of any type of physician's order which would have the effect of withholding or withdrawing life-saving or life sustaining medical care."

DUE PROCESS FIX: Although K.S.A. 59-3075 (e)(7)(C) currently requires that a guardian who desires to withhold or withdraw medical from their ward go to the Court it does not guarantee due process rights to the ward who has the disability. Also as currently written the law says that the court "shall" approve the order and shall approve the request of the Guardian to withhold or withdraw medical care, including food and water. Due process is a right that all Americans are granted under the 14th Amendment of the Constitution of the United States regardless of disability,

and regardless of whether or not they have a disability. DRC has great concern that K.S.A. 59-3075 (e)(7)(C) in its current form violates those rights.

One striking example of how K.S.A. 59-3075 (e)(7)(C) differs from other statutes affecting persons with disabilities in needs of a guardian is K.S.A 59-3075 (e)(5) that addresses the ability of a guardian to forcibly sterilize their ward. "A guardian shall not have the power to consent, on behalf of the ward, to the sterilization of the ward, unless approved by the court following a due process hearing held for the purposes of determining whether to approve such, and during which hearing the ward is represented by an attorney appointed by the court." In this provision due process rights are assured, in (e)(7)(c) due process rights are absent. Kansas law absolutely ensures due process rights before a person with a disability is sterilized, but Kansas law does not does not do so before life sustaining medical care is withheld or withdrawn --- an action that can often lead to death.

HB 2176 addresses the lack of due process by ensuring that the court ". . . afford the ward full and complete due process including, but not limited to, the right to court appointed counsel, notice, hearing, subpoena power, discovery and payment of costs for experts if the ward is deemed indigent." (Page 8, line 29 and following) DRC believes that this provision corrects the current flaw in K.S.A. 59-3075 (e)(7)(C).

DISCRETION FIX: K.S.A. 59-3075 (e)(7)(C) does not provide discretion to the Court when deciding whether or not to allow a guardian to withhold or withdraw medical care from a ward. K.S.A. 59-3075 (e)(7)(C) currently requires that the guardian file a petition with the court requesting authorization to withhold or withdraw medical care from their ward accompanied by the "certification" of two doctors that the ward meets the definition (as described above). It further requires that "Such written certification shall be approved by an order issued by the court" (page 8, line 28), without clear discretion or a clear standard by which to decide the matter.

HB 2176 grants the Court discretion in making a determination, by "clear and convincing evidence" based on the facts presented by the ward's doctor, the guardian, the ward's court appointed attorney and when possible, the ward him, or her self. The decision by the Court is made based on the objective facts presented with an eye toward what the individual with a disability specifically expressed as their intentions for withholding or withdrawing of medical care, or what they likely would have wanted based on the facts presented.

Suggested Changes to HB 2176:

We do have some concerns about some language in the bill and ask you to pay particular attention to these suggestions.

Section 1(d). This section requires court supervision. On page two, line 1, DRC suggests that the word "may" should be changed to "shall." This will afford the ward full due process with the proceedings involving nutrition and hydration. The Judicial Council found that there are very few of these cases every year, therefore ensuring this due process will not be a burden to the courts. Additionally notice should be given to DRC about these cases. As the official Protection and Advocacy System for Kansas, DRC has certain powers under federal law to investigate these claims and may have standing to protect the rights of people with disabilities. Doing this would better ensure complete due process. Also, in this section we would suggest that the burden of proof should increases to "beyond a reasonable doubt," and not left at "clear and convincing."

Section 1(g). This section is quite problematic as written. This section allows for violation of a person with a disabilities' rights if no one objects. By operation it precludes any responsible public official or entity from having standing to intervene if the family and health care provider file a written certification. This is very troubling. Standing is a matter of constitutional law pursuant to Article III of the U.S. Constitution or Article 3 of the Kansas Constitution. A person with a disability represented by and attorney would absolutely have standing for injunctive relief to challenge all family members and health care providers who are attempting to make decisions that would lead to the person's death. But Section 1(g) will put at risk persons with disabilities at the very time they are most vulnerable and most in need of the protection of the state and a fully informed judiciary. A fully informed judge is not a possibility if the person with a disability has no one to speak for them and their advocate cannot even get into the courtroom. This problem is exacerbated because current law allows Guardians to have financial and other conflicts of interest with the ward. Families are allowed to have these same conflicts of interest. These can be intertwined conflicts (Guardian or family are service providers) or more clear cut conflicts, a life insurance policy provides a significant benefit to survivors. We believe that this section should be deleted as it is unnecessary and creates a real danger for persons with disabilities in an otherwise good bill.

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It is important to remember two facts regarding these suggestions: # 1 - If the individual has already provided any kind of written advance directives, e.g., DPOA or living will, then the Court never hears the case; #2 - If # 1 is not met, then under current law the guardian petitions the Court to withhold or withdraw medical care, and the court shall approve the order. **In this light, DRC wants to be crystal clear that our concerns with these two sections should not be seen or used as a reason to not move forward with these changes if consensus cannot be reached on the problematic sections. On a whole, the bill is a dramatic improvement to current law, which is fatally flawed.**

TWO CASE EXAMPLES: As the protection and advocacy system for Kansas, DRC has received several reports where a guardian has either petitioned the Court to withhold or withdraw medical, or has attempted to do it apart from the required Court involvement. Two examples:

Example #1 – A man with mental illness was living at Larned State Hospital as a result of his need for acute mental health treatment. In addition to his mental illness he also required kidney dialysis due to kidney disease. However, he was fully cognizant, had mobility, and actively participated in his treatment. He was placed under guardianship. The ward continued his mental health treatment and steadily improved. His guardian had a petition drafted to allow the guardian to withhold medical care. The guardian had two doctors certify that he was a person with disability who fit the definition in the statute (K.S.A. 59-3075 (e)(7)(C)), and he used "artificial means" (the kidney dialysis machine). The Court, in accordance to the statute approved the certification petition. As a result of the Court authorization of the petition a standing Do Not Resuscitate Order (DNR) was issued at Larned.

The gentleman's health improved and he moved out of Larned into a nursing home for further treatment. The standing DNR followed him to his new residence. He subsequently choked while eating, he was not resuscitated and he died. A DNR and an order to withhold and withdraw medial care are significant, life altering issues. They play a significant role in the matters of life and death.

Example #2 – DRC received a call from a developmental disability service provider in northwest Kansas who reported that a man who has Downs Syndrome was about to have medical care withdrawn. The person with the disability had a bowel obstruction and needed acute medical care. The direct care staff that worked with this gentleman were gravely concerned that his guardian was

making a decision that was not in the best interest of the man with Downs Syndrome. The caller reported that the guardian said that he was "just tired of dealing with him." Because the guardian was "tired," the guardian believed that the person with a disability was disposable. After an initial investigation DRC prepared to intervene on the wards behalf in order to save his life. Fortunately, cooler heads prevailed and the issue was resolved without DRC having to file a lawsuit.

Conclusion

HB 2176 seeks to rebalance the powers of a guardian by: establishing a more clear definition of when medical care can be withheld or withdrawn; establishing clear due process rights that shift the focus of the proceeding on the wishes of the individual, and eliminating the bias in law that says if you have a certain type of disability that your life is not as equal to, or valuable as others; and giving the court discretion in making its decision on all of the relevant facts.

Current law left unchanged will continue the bias against disability and bias that perpetuates bigoted sentiments like "why would anyone want to live like that." You must confront the history of discrimination of people with disabilities. You must confront head-on the absolutely wrong notion that it is better to be dead than disabled. Every study about people with disabilities shows that in the first year after substantial disability, many people experience depression and may consider suicide. But after that first year, and after appropriate services and supports, many realize the true meaning of disability … and that is that disability is good, and normal, and part of life and living. Many then realize the shear power and importance of life and why it is worth living.

Quite simply, death is different. The state has a legitimate interest in preserving the health, welfare, safety and life of its citizens. This state interest must include all people with disabilities, regardless of their label or "condition" that needs "artificial means." The bill attempts to respect the constitutional right to refuse medical care while at the same time ensuring the fullest measure of due process before the state sanctions the death of a person with a disability.

One of the most fundamental duties of society is to ensure that the rights of people with disabilities are protected. The most fundamental right of all is the right to live. If the state is going to have a process that allows the withholding or withdrawing of medical care – including food and water –

that will lead to the death of people with disabilities, it owes people with disabilities the fullest measure of due process, the best definition and a standard for the Court to show discretion. This bill does that.

Testimony
Kansas House of Representatives
Judiciary Committee
February 7, 2007
Topeka, Kansas

In Support of HB 2176

Chairman O'Neal and Committee:

My name is Tammy Coleman & I am a walking, talking miracle of God! I had a bad car wreck when I was twenty-six years old.

I spent about a year & a half in different stages of a coma with a feeding tube. I had to learn how to eat & drink all over again! I had to learn how to walk, talk, write, dress myself, you name it, everything! I remember that I could not even drink water & my mouth would get so dry! I loved sucking on ice chips!

At the time of my car wreck, I was a 1st Lieutenant in the Army Reserves preparing to leave for Germany to serve on active duty & receive my promotion to Captain! I never made it! At the time my plane took off, I was in the Emergency room at Truman West Hospital in Kansas City, Missouri where I was taken to by ambulance, after my car wreck.

I remember being told that one night in ICU there was six other men & myself! They all died & I was the only one still living the next morning!

My car wreck happened less than a mile from my home, where I had been living with my boyfriend, Jim Boring for more than six years. Jim went to court to be appointed as my Legal Guardian. I was so blessed to have such a good legal guardian who loved me very much! And thank God I lived in Missouri.

I am here to support this bill because if my accident happened today in Kansas, and my guardian was not so loving, a judge would be required to allow my feeding tube to be discontinued if the guardian and two doctors wanted it to be.

Jim was my legal guardian for the three years I spent in hospitals & a nursing home, then I was released from the hospital to live with my Father & Stepmother. I lived with them for about three years.

I had to go to court to be appointed as my own legal guardian again. While I was in Research Hospital, my final stop, I had to be tested all day by the neurophysiologist, Dr. Zehr to prove to the court that I could handle all my personal affairs again. When I went to court, the Judge even commented on how well I was doing!

Right after the car wreck, doctors told my family that I would be nothing more than a vegetable, if, I lived! God & I proved them wrong!

Thank you for listening to me! I am still working on improving my speech, my vocal cords were damaged when I had to have a tracheotomy preformed on me in the emergency room to keep me alive!

Tammy Coleman

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House Judiciary
Date 2-7-07
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Testimony to the House Judiciary Committee on HB 2176
February 7, 2007
S313 Capitol Building – Topeka Kansas
John G. Carney, Kansas LIFE Project

Chairman O'Neal and members of the Committee thank you for the opportunity to testify on HB2176. Over the course of about the last 10 years, the Kansas LIFE Project has existed to **help Kansans with advanced chronic and terminal illness live with dignity, comfort and peace.**

The official position of the LIFE Project on HB2176 has been distributed to you. While it delineates a number of concerns that we have regarding definitions and standards in both healthcare and the legal fields as well as the ongoing work of the Judicial Council's special committee on End of Life, I would like to focus my testimony on what I believe are the good intentions underlying this proposal and why those aims don't lend themselves to the adoption of new laws governing the administration of nutrition and hydration

I do not have a medical or nursing background, but I have worked in aging and end of life for more than 20 years. As a non-medical professional working in an arena where the every day complexities of life and death decisions can be at times overwhelming, anguishing and ethically exhausting, I have learned some hard lessons. These are a few:

- Patients and families all too often do not understand the long term impact of their decisions when they make them.
- Unmaking those decisions (when they prove overly burdensome) is far more troubling than even making them.
- There is no such thing as certainty in prognosis, especially in dealing with life threatening conditions. Patients understandably demand it while physicians wisely refrain from it. Prognosis is essential, it's just not certain.
- While we all hope for miracles, we have to live with expectations.

Dr. Anne Allegre, a palliative care physician from the Johnson County, KS area has provided both clarity and conciseness to the complex problem of assisted nutrition and hydration. I would welcome the opportunity to provide you with a complete set of her slides, but in the interest of time I'd like to share a few of her insights that I think are particularly important as you consider this proposal.

- Food and water are considered symbols of caring and nurturance.
- Medically assisted nutrition and hydration are considered by some to be standard medical care.
- Hunger and thirst carry spiritual and religious connotations as well as physical.
- High profile cases make this a subject difficult to speak about.

The reasons for administering artificial nutrition and hydration are dependent upon specific medical conditions with corresponding specific hoped-for outcomes. Evidence based medicine helps us understand that not all hoped for outcomes are achievable depending upon other conditions of patients (accompanying diagnoses, age, prognosis, mental status). These other

factors impact things like increased risk of infection, need for restraint and confinement, sedation, prolongation of suffering, swelling, bloating, congestive failure, lethargy, and pain.

While the attendant symptoms and effects of administering artificial nutrition and hydration may not be life threatening they can be persistent and recurring, significantly complicate care and seriously affect the patient's quality of life as well as unnecessarily lengthen the dying process.

Notwithstanding the good intentions of those who interpret all forms of sustenance as natural and necessary, the medical realities do not support that argument. The decisions about the benefits, burdens and risks of administering artificial nutrition and hydration need to remain in the capable hands of physicians and families, and for wards of the court – approved as current statute dictates by judges. These are often anguishing decisions, made after hours and days of thoughtful and painful deliberation.

It's hard enough to make these decisions at the bedside. We need to do all we can to avoid making them at the bench.

John G. Carney

Vice Chair
Kansas LIFE Project Foundation
Wichita

Vice President
Aging and End of Life
Center for Practical Bioethics
Kansas City

Living Initiatives For End-Of-Life Care

Helping Kansans with advanced chronic and terminal illness live with dignity, comfort and peace

KANSAS LIFE PROJECT POSITION STATEMENT on HB 2176[1]

Summary – The measure presumes that all wards of the court who are incapable of making health care decisions have directed their guardians to provide nutrition and hydration to a degree that is sufficient to sustain life. While the presumption for life provision presents no problems in theory, the specifics of the proposed legislation raise the following concerns:

- It pre-empts the work of the special end of life committee of the Kansas Judicial Council. This group has been working for months to address the types of issues addressed in the bill. At no time has the committee received evidence of abuse of the current system for determining life-sustaining care for wards of the court. No urgency to deal with this matter prior to hearing the special committee's recommendations has been presented. Introducing legislation at this point impedes the work of this broad-based group.

- The measure also:
  1. Subjects the physician's reasonable medical judgment to an unwarranted level of court scrutiny, impeding the practice of medicine. Kansas physicians act in the best interest of patients to preserve life including those of wards of the state. No evidence to the contrary has been presented.
  2. Requires that a written directive must have been executed by the ward in order to withhold treatment rather than allowing other methods of providing clear and convincing evidence, especially by family members.
  3. Suggests that a measure or standard of "objective futility" exists when none does.
  4. Defines the administration of hydration and nutrition "in any manner" as being outside the definition of medical care. This includes surgery to insert feeding tubes. In addition to the benefits, all medical procedures, especially surgeries and the administration of anesthesia carry risks, burdens, and side effects. Kansas statute already requires that life sustaining care be measured, weighed and evaluated by guardian, family, medical professionals and judge. Statutory mandates requiring invasive medical procedures solely for the purpose of providing artificial life support without regard to burden/benefit jeopardizes the dignity of the ward and dismisses the interests of guardians, most of whom are family.

The special committee on end of life of the Judicial Council recognizes the importance of protecting the rights of disabled and vulnerable persons. The committee's work is not completed. Kansans are best served by allowing this group to finish its work; presenting recommendations to the Council that recognize the profound complexity of caring for those who cannot speak for themselves and appropriately involves the interest of the state in protecting vulnerable persons in these matters.

[1] Approved February 6, 2007.

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Public Testimony
Judiciary Committee
Kansas House of Representatives
House Bill 2176
February 7, 2007

Chairman O'Neal, Members of the House Judiciary Committee,

Thank you for the opportunity to share my concerns about medical decisions for artificial nutrition and hydration. I am a hospice nurse with more than twenty-five years of experience in end-of-life care. Hospice promotes a world where individuals and families facing serious illness, death and grief will experience the very best that humankind can offer.

Decisions about withholding or withdrawing artificial nutrition and hydration (ANH) should be made in the same manner as decisions about other medical treatments. House Bill 2176 defines the administration of hydration and nutrition "in any manner" as being outside the definition of medical care. However, medical procedures to artificially administer nutrition and hydration carry risks, burdens, side effects and benefits which should considered and evaluated by the patient, family and medical professional. House Bill 2176 reduces the physician's reasonable medical judgment and practice of medicine to court scrutiny. No evidence was cited to suggest Kansas physicians are not acting in the best interest of patients and their commitment to preserve life. Physicians and nurses must complete required education, pass state boards, and seek continued education for license renewal. The focus for physicians and nurses is to provide the very best care for each individual. Professional Codes of Conduct for practitioners exist to protect patients.

House Bill 2176 presumes that all wards of the court incapable of making health care decisions have directed their guardians to provide nutrition and hydration to a degree that is sufficient to sustain life. It requires a written directive must have been executed by the ward to withhold nutrition and hydration. That level of proof is simply beyond what can be expected of most any person and grossly oversimplifies the complexities of care of persons living with lifelong disabling conditions. The U.S. Supreme Court in the 1990 Cruzan case established the evidentiary standard as "clear and convincing," allowing for arguments by family and friends to suffice in such instances. That standard is more than adequate.

I have concern about the intent and language of this bill. In 2005, a Kansas Judicial Council Committee with representation from across Kansas and a variety of fields was named to study this issue. The committee was committed to draft appropriate language to protect our most vulnerable without taking away the individual's and family members' sense of autonomy and individuality, their ability to make decisions in the best interest of the individual. Our work on that Committee continues to this day and I ask that you delay any consideration of pre-empting that work until we have a chance to complete it. There is no urgency in this matter.

Sandy Kuhlman, RN, Executive Director
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House Judiciary
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