No. 88-1503

IN THE

Supreme Court of the United States

OCTOBER TERM, 1989

NANCY BETH CRUZAN, by her parents and co-guardians,
LESTER L. AND JOYCE CRUZAN.

Petitioners,

v.

DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH
AND ADMINISTRATOR OF THE MISSOURI
REHABILITATION CENTER AT MT. VERNON,

Respondents,

v.

THAD C. McCANSE, GUARDIAN AD LITEM,

Respondent.

On Writ of Certiorari
to the Supreme Court

BRIEF OF THE AMERICAN HOSPITAL ASSOCIATION AS AMICUS CURIAE IN SUPPORT OF PETITIONERS

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TABLE OF CONTENTS

TABLE OF AUTHORITIES

Cases

Statutes

American Hospital Association Policies, Statements or Guidelines

	Page
National Conference of Commissioners on Uniform State Laws, *Uniform Rights of the Terminally Ill Act* (1985)	9
Neu and Kjellstrand, *Stopping Long-Term Dialysis,* 314 New Eng. J. Med. 14 (1986)	10
The New York State Task Force on Life and the Law, *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (1987)	9
Newman, *Treatment Refusals for the Critically Ill: Proposed Rules for the Family, the Physician and the State,* III N.Y.L. Sch. Human Rights Annual, Part One (1985)	9
President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (1983)	7, 9, 12
Rhoden, *Litigating Life and Death,* 102 Harv. L. Rev. 375 (1988)	9
Ruark, Raffin, and the Stanford University Medical Center Committee on Ethics, *Initiating and Withdrawing Life Support,* 318 New Eng. J. Med. 25 (1988)	10
Silva and Kjellstrand, *Withdrawing Life Support: Do Families and Physicians Decide as Patients Do?,* 48 Nephron 201 (1988)	10
United States National Center for Health Statistics, 37 Monthly Vital Statistics 6 (1989)	3
United States National Center for Health Statistics, *Vital Statistics of the United States* (1986)	3
Wanzer, *et al.*, *A Physician's Responsibility Toward Hopelessly Ill Patients,* 310 New Eng. J. Med. 955 (1984)	13

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INTEREST OF THE *AMICUS CURIAE*

Amicus curiae, the American Hospital Association (AHA), respectfully submits this brief in support of the Petitioners. The AHA has obtained the written consent of both the

Petitioners and the Respondents to the filing of this brief *amicus curiae*.[1]

Founded in 1898, the AHA is the primary organization of hospitals in the United States. Its membership includes 71% of the nation's 7,051 hospitals, and 81% of the nation's 1,265,967 hospital beds.[2] Forty-eight thousand health care professionals hold individual membership in the AHA.

The AHA's corporate mission is to promote the quality of American health care and health services for all people through leadership and assistance to hospitals and health care organizations. To fulfill this mission, AHA regularly participates in important issues in the judicial and legislative arena.

The AHA has played a leadership role in the ongoing debate concerning biomedical ethical issues. Through its Special Committee on Biomedical Ethics, the AHA has published policies and positions addressing the role of patients, families, guardians, physicians and hospitals involving the withholding and withdrawal of medical treatment. Further, the AHA's bimonthly publication, *Hospital Ethics*, offers a forum for learned discussion of biomedical ethical issues.

As a leader in the health care field, as the representative of those institutions where the withholding and withdrawal of treatment occurs and as a contributor to the biomedical ethical debate, the AHA is vitally concerned about the heightened anguish, time and expense which will be forced upon patients, families, providers and society should the opinion and reasoning of the Missouri Supreme Court be affirmed.

SUMMARY OF ARGUMENT

Everyday in American hospitals thousands of decisions to forego life-sustaining medical treatment are made. These

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[1] The letters providing consent from all parties have been filed with the Clerk of the Court.

[2] AHA, *Hospital Statistics* (1988).

decisions are arrived at within a collaborative relationship among patients, families, physicians and institutions. Hospital policies and procedures foster this time-honored process in an informed, compassionate and ethical manner, obviating the necessity for constant judicial scrutiny.

The American Hospital Association submits that the past pronouncements of this Court respect the rights of patients, families and health care providers to participate in this most sacred of human decisions.

ARGUMENT

Approximately 2.2 million Americans die each year.[3] One million three hundred thousand of these people die in hospitals.[4] Seventy percent die after a decision to forego life-sustaining treatment has been made.[5]

The plight of Nancy Beth Cruzan is indeed tragic, but it is not unique. Decisions to forego life-sustaining medical treatment are made in this nation's hospitals every day. Almost all of these decisions are made privately by the patient, family and physician. It is the rare case that surfaces in the public domain.

Informed, compassionate, ethical decisionmaking routinely occurs at the institutional level. This Court should reject the Missouri Supreme Court's invitation for constant judicial involvement in medical treatment decisions.

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[3] United States National Center for Health Statistics, 37 Monthly Vital Statistics 6 (1989).

[4] United States National Center for Health Statistics, *Vital Statistics of the United States* (1986).

[5] Lipton, McNamee and Campion, *Do-Not-Resuscitate Decisions in a Community Hospital: Incidence, Implications and Outcomes,* 256 JAMA 1164 (1986).

I. THE AMERICAN HOSPITAL ASSOCIATION'S POLICIES AND PROTOCOLS ON MEDICAL DECISIONMAKING ARE DEEPLY ROOTED IN RESPECT FOR INDIVIDUAL AUTONOMY.

In 1972, the American Hospital Association's Board of Trustees approved its policy statement on *A Patient's Bill of Rights* and in February and April of 1985 the Board approved respectively the works of its Special Committee on Biomedical Ethics entitled *Patient's Choice of Treatment Options,* App. *infra,* A., B., and *Values in Conflict: Resolving Ethical Issues in Hospital Care.*[6]

Under these policies, the patient's role as the focal point of medical decisionmaking must be ensured in the institutional setting. Although these decisions should be made in collaboration with the attending physician, the hospital must take a leadership role by establishing institutional practices that support patient decisionmaking and identify when recourse to the judgment of others is necessary.

The foundation of these policy principles is consonant with pronouncements of this Court, which as early as 1891 affirmed that individuals are sovereign over their own persons: "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." *Union Pacific Railway Company v. Botsford,* 141 U.S. 250, 251 (1891).

More recently, this Court has characterized this principle of self determination as a liberty interest protected by

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[6] AHA Policy: *A Patient's Bill of Rights* (1972); AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985); AHA, *Values in Conflict: Resolving Ethical Issues in Hospital Care* (1985). Portions of these American Hospital Association policies are reproduced in the Appendix of this Brief.

the Due Process Clause of the Fourteenth Amendment and as a privacy right which springs from the protections under the Bill of Rights. *See Griswold v. Connecticut*, 381 U.S. 479 (1965); *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Roe v. Wade*, 410 U.S. 113 (1973); *Doe v. Bolton*, 410 U.S. 179 (1973); *Parham, Commissioner, Department of Human Resources of Georgia v. J.R.*, 442 U.S. 584 (1979); and *Youngberg v. Romeo*, 457 U.S. 307 (1982).

While this Court has not directly addressed an individual's constitutional right to refuse life-prolonging medical treatments,[7] since the New Jersey Supreme Court's seminal decision concerning the plight of Karen Ann Quinlan, *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976), numerous state courts have affirmed the prerogatives reflected in the American Hospital Association's commitment to respect for patient decisions.[8]

Citing this Court and specific articles of the New Jersey constitution, the *Quinlan* court held: "Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain circumstances." *Quinlan*, 70 N.J. at 40.

Furthermore, forty states and the District of Columbia have enacted so-called "living will" statutes which foster the exercise of the fundamental right to order one's medical liber-

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[7] *Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988), upheld the federal constitutional right of an incompetent patient to forego the artificial provision of nutrition and hydration. No appeal was taken.

[8] Ironically, while denying these decisional prerogatives to Nancy Cruzan, the Missouri Supreme Court ably catalogues over 50 cases in 16 states which vindicate the treatment elections of the Cruzan family. *Cruzan, by Cruzan v. Harmon*, 760 S.W.2d 408, 412-413 n.4 (Mo. banc. 1988).

ties.[9] Such initiatives countenance recognition and vindication of individual treatment choices which form the core of the American Hospital Association's long standing policies respecting individual medical decisionmaking: ". . . the authority to determine the course of treatment, if any, should rest with the patient . . . . The right to choose treatment includes the right to refuse a specific treatment or all treatment, or select an alternative form of treatment. AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985). App. *infra*, B.

Accordingly, the principle that competent individuals are sovereign over their own persons and can ordain the disposition of their bodies is widely recognized. The members of the American Hospital Association routinely rely upon this fundamental maxim when providing care to all patients.

II. THE AMERICAN HOSPITAL ASSOCIATION BELIEVES THAT TREATMENT DECISIONS FOR PATIENTS LACKING DECISIONMAKING CAPACITY SHOULD BE MADE AT THE INSTITUTIONAL LEVEL BY THE FAMILY IN CONSULTATION WITH HEALTH CARE PROVIDERS

A. Families Are Presumptively The Appropriate Locus Of Medical Treatment Decisions For Patients Lacking Decisionmaking Capacity.

The right of self determination vouchsafed to a competent patient can and should be exercised by that patient's family should the patient lack decisionmaking capacity.[10] The policies and protocols of the American Hospital Association

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[9] For a list of these states *see In re Farrell*, 108 N.J. 335, 342 n.2, 529 A.2d 404, 407 n.2 (1987).

[10] The AHA believes that "family" includes those related by blood or marriage, as well as friends and loved ones as recognized under state law.

contend that those in a position to know and appreciate the totality of an incompetent person's approach to life are the ones who should be entrusted with decisionmaking power in their regard.[11] The AHA submits that it is the family who is most able to advocate the patient's wishes and to assess the patient's purposes and experiences.

Throughout history it has been the family's duty and responsibility to attend to the sick and dying. Death was primarily a private matter which occurred in the confines of the home. With the development of health care institutions and modern medical technology, the situs of death has shifted from the home to the institution.[12] Yet it was, and will continue to be, the family which remains the primary source of comfort for the dying individual.

This Court has long recognized the family as the appropriate surrogate on behalf of its members lacking decisionmaking capacity. The right of the family to make fundamental decisions affecting the lives of its members received initial acceptance in *Meyer v. Nebraska*, 262 U.S. 390 (1923). Two years later, in *Pierce v. Society of Sisters*, 268 U.S. 501, 535 (1925), this Court, citing the *Meyer* decision, reaffirmed the constitutional notion of a family's duties and obligations to exercise rights on behalf of their incompetent own: "The child is not the mere creature of the State; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations."

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[11] Patient's prior directives, whether written or oral should, of course, be heeded. Where conflict exists concerning these directives, recourse to institutional or judicial review would be appropriate. *See* AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985). App. *infra*, B.

[12] *See* President's Commission for The Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 17 (1983).

More recently, in *Parham, Commissioner, Department of Human Resources of Georgia v. J.R.*, 442 U.S. 584, 602 (1979), the Court stressed the historical "... concepts of the family as a unit with broad parental authority over minor children," and the recognition "... that the natural bonds of affection lead parents to act in the best interest of their children" when they must be hospitalized for psychiatric care. This same Court further interpreted past precedents in favor of a presumption that parents should be able to make decisions regarding the medical treatment of their children: "[W]e conclude that our precedents permit the parent to retain a substantial, if not dominant, role in the decision, absent a finding of neglect or abuse, and that the traditional presumption that the parents act in the best interests of their child should apply." *Parham*, 442 U.S. 604.[13]

As in *Parham*, this Court in *Michael H. and Victoria D. v. Gerald D.*, 109 S.Ct. 2333, 2342 (1989), again underscored the time-honored trust and respect reposed in the American family: "... sanctity would not be too strong a term—traditionally accorded to the relationships that develop within the unitary family."

Building upon these foregoing principles, state supreme courts have generally embraced the notion that family members of patients lacking decisionmaking capacity are the proper parties to make substituted medical judgments on their behalf. The New Jersey Supreme Court fairly reflects the evolving national consensus:

> Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but

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[13] The wisdom of the Court's description of the parent's powerful role in making decisions for children who lack decisionmaking capacity due to age, is no less apt for the present situation where Nancy Cruzan's parents wish to make a decision for their child lacking decisionmaking capacity due to illness.

> also because of their special bonds with him or her. Our common human experience informs us that family members are generally most concerned with the welfare of a patient. It is they who provide for the patient's comfort, care and best interests . . . , and they who treat the patient as a person, rather than a symbol of a cause . . . . We believe that a family member is generally the best choice [to make medical treatment decisions].

In re Jobes, 108 N.J. 394, 415-416, 529 A.2d 434, 445 (1987) (*quoting* Newman, *Treatment Refusals for the Critically Ill: Proposed Rules for the Family, the Physician and the State,* III N.Y.L. Sch. Human Rights Annual, Part One 45-46 (1985)).

Indeed, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in *Deciding to Forego Life-Sustaining Treatment* (1983), the Hastings Center in *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (1987), the Congress of the United States Office of Technology Assessment in *Life-Sustaining Technologies and the Elderly* (1987), The New York State Task Force on Life and the Law in *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent*, Professor Rhoden in *Litigating Life and Death,* 102 Harv. L. Rev. 375 (1988), Professor Newman in *Treatment Refusals for the Critically Ill: Proposed Rules for the Family, the Physician and the State,* III N.Y.L. Sch. Human Rights Annual, Part One (1985) and the National Conference of Commissioners on Uniform State Laws in the *Uniform Rights of the Terminally Ill Act* (1985) have all affirmed the fundamental belief in the integrity of the family, physician and the institution as proper cooperators in the necessarily difficult decisions concerning patients lacking decisionmaking capacity.

Support for the family as a surrogate decisionmaker for patients lacking decisionmaking capacity abounds as well in the medical literature. Not only is the importance of family paramount, but physicians are encouraged to involve them early in decisions concerning the withholding and withdrawal of medical treatment for such patients. Ruark, Raffin, and the Stanford University Medical Center Committee on Ethics, *Initiating and Withdrawing Life Support*, 318 New Eng. J. Med. 25 (1988). *See also* Carlson, Devich and Frank, *Development of a Comprehensive Supportive Care Team for the Hopelessly Ill on a University Hospital Medical Service*, 259 JAMA 378 (1988).

Empirical support for the acceptance of the family as the primary community of decisionmaking is to be found in a recent study which concluded that families, in collaboration with health care providers, make decisions which best reflect treatment elections made by patients themselves: "We believe the result of our study is reassuring and indicates that substitute judgement is used wisely. There is no difference in any important aspect between the competent patients who decide to stop dialysis and die and the incompetent patients for whom the decision is made by someone else." Silva and Kjellstrand, *Withdrawing Life Support: Do Families and Physicians Decide as Patients Do?*, 48 Nephron 201, 204 (1988). *See also* Neu and Kjellstrand, *Stopping Long-Term Dialysis*, 314 New Eng. J. Med. 14 (1986).

The AHA has consistently supported a continuing faith in the traditional decisionmaking framework, allowing for the exercise of individual treatment decisions on behalf of patients lacking decisionmaking capacity by those who know and love the patient most dearly—the family.

> [T]he best substitute for an incapacitated patient is a surrogate who can take action consistent with the previously expressed or known wishes of the patient . . . . If the patient has never designated a surrogate, then health care professionals should work together to find family members who are in a position to know what the incapacitated patient would have wanted to do in the situation at hand.

AHA, *Legal Memorandum Number Nine–Discharging Hospital Patients: Legal Implications for Institutional Providers and Health Care Professionals* 12-13 (1987).

Thus, the legal, medical and scholarly communities recognize that medical treatment decisions should be exercised by the family, on behalf of patients lacking decisionmaking capacity. Every day, in the nation's hospitals, family treatment choices reflect informed, compassionate and ethical decisionmaking.

B. Treatment Decisions Made By The Family Occur In Collaboration With Health Care Providers.

Notwithstanding the primary role of the family in making treatment choices for their incapacitated loved ones, individual treatment decisions are never made in isolation. Rather, decisionmaking is based on a collaborative relationship among the family, physician and other health care professionals who are primarily responsible for the patient's care. Institutional policies and procedures also foster the decisionmaking process, assuring that decisions to withhold or withdraw medical treatment are structured to respect patient and family wishes within the bounds of medical, ethical and legal confines. This collaborative process is the cornerstone of medical decisionmaking in hospitals across the land.

1. The Responsibility For Assuring The Integrity Of Medical Decisionmaking Falls First To The Attending Physician.

As health care providers and as architects of the patient care plan, physicians bear the primary responsibility for assuring that family decisionmaking is the product of an informed judgment premised upon sound medical and ethical prescriptions.

Physicians fulfill this role within the accepted doctrines of the physician-patient relationship and informed consent to medical treatments. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972).

Within the physician-patient relationship, physicians have a legal and ethical duty to the patient to ensure that treatment decisions are made which foster and protect the patient's best interests. *See* American Medical Association, *Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association*, Opinion 2.18 (1986). This duty does not end once a patient lacks decisionmaking capacity – the physician maintains his obligations and allegiance to the patient.[14] The physician-patient relationship, therefore, plays a critical role in guarding the patient from surrogate treatment decisions which are inconsistent with sound medical practice and ethical conduct.

Central to the safeguards of the decisionmaking process among the patient, family and physician is the notion of informed consent. Generally, there are three basic prerequisites for informed consent: (1) The patient must have the capacity to reasonably make judgments; (2) the patient must have a clear understanding of the nature of the disease and his prognosis, as well as the risks and benefits of the proposed treatment alternatives; and (3) the decision must be made voluntarily and without coercion. Applebaum and Grisso, *Assessing Patients' Capacities to Consent to Treatment,* 319 New Eng. J. Med. 1635 (1988).

Ordinarily, the patient's decisionmaking capacity is presumed unless questions arise concerning the patient's cognitive processes. In such instances, it is the physician's duty to make an assessment of the patient's decisionmaking capacity before accepting any decision about medical care. *Presi-*

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[14] Physicians, of course, are under a continuing duty to honor the incapacitated patient's previously expressed desires regarding the use of life support. In some cases, living wills or durable powers of attorney or other statements may help to clarify these desires.

dent's Commission at 45. If a patient is found to have decisionmaking capacity, the patient's judgments will be honored. To foster this protective process, only in those instances where a patient is found to lack such capacity will the physician turn to the family for a treatment decision.[15]

To ensure that families have a clear understanding of the nature of the disease and the risks and benefits of proposed treatments, the physician must provide them with the diagnosis, possible courses of treatment, all material risks of the treatment options including the degree of hazard of each choice, and the benefits and disadvantages of the various treatment elections as well as the risk and benefit of non-treatment. *See* Wanzer, *et al.*, *A Physician's Responsibility Toward Hopelessly Ill Patients,* 310 New Eng. J. Med. 955 (1984); Applebaum and Grisso, *Assessing Patients' Capacities to Consent to Treatment,* 319 New Eng. J. Med. 1635 (1988). This information protects patients by assuring that treatment decisions are grounded in sound medical advice.

Finally, a family's treatment choice should be uninfluenced by coercion. It is the role of the physician to assist the family in making treatment decisions which are medically warranted for that patient. American Medical Association, *Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association,* Opinions 2.18, 2.19 (1986).

Physicians collaborate with families in making treatment decisions. Through the physician-patient relationship and the doctrine of informed consent, the physician assists the fam-

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[15] These determinations are generally made without resort to any formal legal process. When an incapacitated patient lacks any close family members or friends, or when the determination regarding decisionmaking capacity is controversial among concerned persons (including the patient), legal guardianship proceedings may be considered. *See* AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985). App. *infra*, B.

ily in assuring that treatment decisions for patients lacking decisionmaking capacity are respectful of patient sovereignty and are in keeping with accepted medical, ethical and legal principles. *See* AHA Policy: *A Patient's Bill of Rights* (1972). App. *infra*, A.

2. *Hospitals Play An Important Role In Fostering And Guiding Medical Decisionmaking.*

While the physician is responsible for advising the patient and family and supervising the course of treatment, the hospital, through its institutional policies, plays an important role in fostering and guiding medical decisionmaking. Further, through its staff and available institutional advisory mechanisms, such as ethics committees, the hospital strives to ensure the integrity of decisionmaking about life-sustaining treatment.[16]

Hospital policies and procedures constitute important safeguards for the decisionmaking process. First, hospital policies establish a framework for determining a patient's decisionmaking capacity.[17] The American Hospital Association's Policy and Statement on *Patient's Choice of Treatment Options*, App. *infra*, B., states that institutions should have effective policies to facilitate assessment of patients' decisionmaking capacity. Specifically, the institution should have methods to ensure that the physician conducts these assessments when necessary. The hospital should also see to it that there are accessible and practical avenues by which concerns about a patient's capacity to make decisions may be raised

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[16] *See* AHA Guidelines: *Hospital Committees on Biomedical Ethics* (1984). App. *infra*, D.

[17] The actual determination of decisionmaking capacity is made by the physician relying upon his or her medical judgment. AHA, *Values in Conflict: Resolving Ethical Issues in Hospital Care* 16 (1985).

by others, including family, friends, nurses and other health care professionals.

Second, hospitals employ policies governing the obtaining of informed consent. These policies are required by the Joint Commission on Accreditation of Health Care Organizations (JCAHO) and, by reference, the federal Medicare program. JCAHO, *Accreditation Manual for Hospitals*, Medical Record Services Standard MR. 2.2.71 at 91 (1989); 42 U.S.C. §1395bb(a)(1)(1989).[18] These JCAHO standards require that the medical record contain evidence that informed consent has been obtained for procedures and treatments under these informed consent policies. In daily practice, hospitals provide for the documentation of such informed consent.

The AHA is supportive of hospitals maintaining policies to assure the obtaining of informed consent. In its Guidelines entitled *Ethical Conduct for Health Care Institutions* (1987), App. *infra*, C. , the AHA states that health care institutions should have policies and practices that support the process of informed consent for diagnostic and therapeutic procedures and that respect and promote the patient's responsibility for decisionmaking.

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[18] JCAHO, formerly the Joint Commission on Accreditation of Hospitals, is a private, voluntary, accrediting body whose basic purposes are to establish standards for the operation of health care facilities, to conduct survey and accreditation programs that encourage and assist health care facilities in the task of promoting efficient, high quality patient care, and to recognize compliance with their standards by issuance of certificates of accreditation. JCAHO has five member organizations which appoint commissioners to its Board: American Hospital Association, American Medical Association, American College of Surgeons, American College of Physicians and the American Dental Association. An additional commissioner is appointed by the Board from the general public. Many states also accept JCAHO accreditation as evidence of compliance with their own licensing standards.

Third, hospital policies governing the withholding and withdrawal of medical treatment also safeguard the decisionmaking process.[19] These policies typically provide a framework for making treatment decisions for incompetent patients, including identification of procedures for securing informed consent, determination of surrogates, guidelines for documenting the withholding or withdrawal of treatment, as well as detailing when recourse to available institutional advisory mechanisms is appropriate. *See generally* AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985). App. *infra,* B.

Finally, hospital policies set forth procedures to determine appropriate surrogate decisionmakers. While the content of these policies varies due to state law and institutional characteristics (such as religious affiliation), the policies are often quite specific as to the determination of the appropriate surrogate.

Thus, nationwide, hospitals have historically developed and maintained protocols to enhance decisionmaking by families and physicians. These policies have clearly and effectively provided for compassionate treatment decisions on a daily basis with the rare need to seek judicial review.

CONCLUSION

Decisions to forego or withhold life-sustaining medical treatment are made on a daily basis in hospitals and other health care institutions throughout this country. The American Hospital Association believes that the existing institutional-based procedures for making these decisions for patients lack-

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[19] Since January 1988, all hospitals have been required to develop written policies governing the withholding of resuscitative services from patients. JCAHO, *Accreditation Manual for Hospitals,* Management and Administrative Services Standard MA.1.4.11 at 82 (1989).

ing decisionmaking capacity adequately ensure that they are made with care, dignity and respect for patient sovereignty.

The policies of the AHA strive to foster individual, familial and surrogate decisionmaking within the longstanding framework of the physician-patient relationship and the informed consent doctrine. Required judicial involvement, flowing from the decision of the Missouri Supreme Court, would wreak havoc on this time-honored process which has served patients, families and health care providers well.

Accordingly, the American Hospital Association, as Friend of the Court, respectfully urges this Court, for all the foregoing reasons, to reverse the majority decision of the Missouri Supreme Court.

Respectfully submitted,

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