No. SC04-925
Lower Tribunal No. 2D04-2045

IN THE SUPREME COURT OF FLORIDA

JEB BUSH, Governor of the State of Florida,

Appellant,

vs.

MICHAEL SCHIAVO, as guardian of the person of THERESA MARIE SCHIAVO,

Appellee.

AMICUS CURIAE BRIEF IN SUPPORT OF MICHAEL SCHIAVO AS GUARDIAN OF THE PERSON OF THERESA MARIE SCHIAVO (FILED WITH THE CONSENT OF THE PARTIES)

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INTRODUCTION

The extraordinary circumstances of this case implicate the philosophy of bioethics – the study of moral and ethical issues in medical practice and research.

This amicus curiae brief in support of Michael Schiavo as guardian of the person of Theresa (Terri) Marie Schiavo is filed (with the consent of all parties) by fifty-five of the nation's leading bioethicists. They include hospital ethics program directors, ethics committee members, medical ethics advisors and consultants, bioethics scholars and researchers, medical and law school professors, practicing physicians, and moral theologians of the Catholic, Protestant and Jewish faiths. (The fifty-five bioethicists are listed by name and title at pages v-ix, *supra*.) The bioethicists are interested in this case because this Court's decision will affect their health care and bioethical practices and teachings in hospitals and schools throughout the United States.

Also joining this brief is Autonomy, Inc., a disability rights advocacy organization whose mission is to represent the interests of people with disabilities who wish to be able to exercise choices concerning all aspects of their lives, including choices at the end of life. Autonomy, Inc. believes that end-of-life choices are a private matter to be determined by the individual and that people with disabilities should maintain decision-making autonomy throughout their lives. Autonomy, Inc. is

interested in this case because this Court's decision will affect the rights of disabled persons and their proxies to refuse unwanted medical treatment.

The Appellee's Answer Brief explains how Ch. 2003-418 violates Terri Schiavo's constitutional right of personal autonomy by authorizing the Governor to override her wishes regarding her medical treatment. In this amicus curiae brief we explain the bioethical principles underlying that constitutional right and governing surrogate exercise of an incompetent patient's right to refuse medical treatment, and how Ch. 2003-418 violates those bioethical principles.

BACKGROUND

I. THE BIOETHICAL CONTEXT.

A. The Central Value of Personal Autonomy.

Bioethicists have identified four "central values" that arise "from the moral traditions of medicine and nursing and from the ethical, religious, and legal traditions of our society." Hastings Center, Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying, at 6-7 (1987) [hereinafter Hastings Center Guidelines]. One of these values is *beneficence*, which acknowledges that "the proper goal of medicine is to promote the patient's well-being." *Id.* at 7. Another is *the integrity of health care professionals*, who "have a right to remain true to their own conscientious moral and religious beliefs." *Id.* at 8. A third is *justice*, which

"demands that individuals have an opportunity to obtain the health care they need on an equitable basis" yet "places ethical limits on the patient's liberty to demand, rather than forgo, scarce medical resources." *Ibid.*

The remaining central value is *personal autonomy*, "which establishes the right of the patient to determine the nature of his or her own medical care." *Id.* at 7. Protecting the right of personal autonomy "reflects our society's long-standing tradition of recognizing the unique worth of the individual. We respect human dignity by granting individuals the freedom to make choices in accordance with their own values." *Ibid.*

Some patients are incapable of making decisions about their health care. In such situations, it is generally accepted that "[i]f a patient lacks decisionmaking capacity, *respecting autonomy means that an appropriate surrogate . . . should make decisions*" on the patient's behalf. *Id.* at 7-8 (emphasis added).

B. Surrogate or Proxy Exercise of Personal Autonomy: Advance Directives, Substituted Judgment, and Best Interests.

Bioethicists have prescribed three models for surrogate exercise of an incompetent patient's right of personal autonomy, under the guiding principle that "the surrogate should seek to choose as the patient would if he or she were able." *Id.* at 27.

The first model applies if the patient previously gave an *advance directive* describing his or her wishes. "Where a patient who had decisionmaking capacity at the time, has left written directions in an advance directive . . . or another form, or clear oral directions, and these directions seem intended to cover the situation presented, *the surrogate should follow the directions*." *Id.* at 28 (emphasis added).

The second model is invoked where there is no advance directive but the patient has otherwise made known his or her *preferences and values*. "If the patient has left no directions about the treatment in question, the surrogate should apply what is known about the patient's preferences and values, trying to choose as the patient would have wanted." *Ibid.* This model, which like the first model focuses on the patient's subjective wishes, is commonly called *substituted judgment*.

The third model involves determining the patient's *best interests* when nothing is known about his or her wishes. "If there is not enough known about the patient's directions, preferences, and values to make an individualized decision, the surrogate should choose so as to promote the patient's interests as they would probably be conceived by a reasonable person in the patient's circumstances, selecting from within the range of choices that reasonable people would make." *Ibid.* The best interests model, however, is the model of last resort. "[W]hen possible, decisionmaking for incapacitated patients should be guided by the principle of substituted judgment, which promotes the underlying values of self-determination and well-being better than the

best interests standard does." President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment, at 136 (1983) [hereinafter President's Commission report].

The present case implicates the second bioethical model for surrogate decision-making – a substituted judgment decision based on the patient's known preferences and values as determined by the surrogate.

II. THE LEGAL CONTEXT.

A. The Constitutional Right of Personal Autonomy.

The central value of personal autonomy is where bioethics intersects with the law.

No legal right is more important in American society than the right of personal autonomy – each person's "fundamental right to the sole control of his or her person." *In re Guardianship of Browning*, 568 So. 2d 4, 10 (Fla. 1990). "An integral component of self determination is the right to make choices pertaining to one's health, including the right to refuse unwanted medical treatment." *Ibid.* This right is guaranteed by the privacy provisions of Article 1, Section 23 of the Florida Constitution. *Id.* at 10; *see also id.* at 11, 13. It is also guaranteed by the Due Process Clause of the Fourteenth Amendment to the United States Constitution. *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 278 (1990). The right of personal

autonomy has also been embraced by the Florida Legislature in a finding that "every competent adult has the fundamental right of self-determination regarding decisions pertaining to his or her own health, including the right to choose or refuse medical treatment." § 765.102(1), Fla. Stat. (2004).

The right of personal autonomy is not extinguished by incompetency. "[A]n incompetent person has the same right to refuse medical treatment as a competent person." *Browning*, 568 So. 2d at 12.

B. Surrogate or Proxy Exercise of Personal Autonomy.

When a patient is incompetent, the decision whether to refuse medical treatment must be made by a surrogate or proxy. The Florida Legislature has prescribed standards for exercise of an incompetent person's right to refuse treatment in order to "ensure that such right is not lost or diminished by virtue of later physical or mental incapacity . . . " § 765.102(1), Fla. Stat. (2004). These standards align precisely with the three bioethical models for surrogate exercise of the right of personal autonomy.

1. The first bioethical model: instructions in an advance directive.

First, if an incompetent patient has given instructions or expressed his or her desires in an *advance directive* that designates a surrogate to make health care decisions on the patient's behalf, the surrogate must act *in accordance with the patient's instructions*. § 765.205(1), Fla. Stat. (2004). Similarly, if the patient has executed a living will expressing his or her desires concerning life-prolonging procedures but has not designated a surrogate, the patient's physician may proceed as directed in the living will. § 765.304(1), Fla. Stat. (2004).

These legislative provisions implement the first bioethical model: adherence to instructions in an advance directive.

2. The second bioethical model: substituted judgment.

Next, if the incompetent patient has not executed an advance directive or living will, health care decisions are made by a *proxy* in the following order of preference: (1) a previously-appointed guardian for a person with a developmental disability, (2) a spouse, (3) an adult child or adult children, (4) a parent, (5) an adult sibling or adult siblings, (6) an adult relative who has exhibited special care and concern for the patient, (7) a close friend, or (8) a licensed clinical social worker selected by a health care provider's bioethics committee. § 765.401(1), Fla. Stat. (2004). The proxy must

make the health care decision that "the proxy reasonably believes the patient would have made under the circumstances." § 765.401(2), Fla. Stat. (2004).

This legislative provision implements the second bioethical model: a substituted judgment decision based on the patient's known preferences and values.

"[I]t is important for the surrogate decision-maker to fully appreciate that he or she makes *the decision which the patient would personally choose*. In this state, we have adopted a concept of 'substituted judgment.' One does not exercise another's right of self-determination or fulfill that person's right of privacy by making a decision which the state, the family, or public opinion would prefer. The surrogate decisionmaker must be confident that he or she can and is voicing *the patient's decision*." *Browning*, 568 So. 2d at 13 (emphasis added, citation omitted).

3. The third bioethical model: best interests.

Finally, if there is no indication what a patient would have chosen, so that a proxy cannot make a substituted judgment decision, then – and only then – "the proxy may consider the patient's best interest in deciding that proposed treatments are to be withheld or that treatments currently in effect are to be withdrawn." § 765.401(2), Fla. Stat. (2004).

This legislative provision implements the third bioethical model, the course of last resort: a decision based on the patient's *best interests* as they would probably be conceived by a reasonable person in the patient's circumstances.

C. The Judge As Proxy.

Under Florida law, a proxy may present a health care decision to the circuit court for judicial resolution. *Browning*, 568 So. 2d at 16. "In this context, the trial court essentially serves as the ward's guardian." *In re Guardianship of Schiavo (Schiavo I)*, 780 So. 2d 176, 179 (Fla. 2d DCA 2001). Michael Schiavo took that approach for Terri Schiavo. *Ibid.*

Even here, the law's preference is for a substituted judgment decision under the second bioethical model. "It is the trial judge's duty not to make the decision that the judge would make for himself or herself or for a loved one. Instead, the trial judge must make a decision that the clear and convincing evidence shows the ward would have made for herself." *In re Guardianship of Schiavo (Schiavo IV)*, 851 So. 2d 182, 187 (Fla. 2d DCA 2003).

ARGUMENT

I. CHAPTER 2003-418 VIOLATES BIOETHICS BY PLACING SUBSTITUTED JUDGMENT DECISION-MAKING AUTHORITY IN THE HANDS OF AN INAPPROPRIATE PROXY WHO KNOWS NOTHING OF TERRI SCHIAVO'S WISHES.

The purpose of surrogate decision-making on behalf of an incompetent patient is to fulfill the wishes of the patient. That purpose is best served by appointment of an "appropriate" surrogate. Hastings Center Guidelines, *supra*, at 7. "[T]he goal is to find the person who is most involved with the patient and most knowledgeable about the patient's present and past feelings and preferences." *Id.* at 24.

Where the patient has not designated a surrogate, the bioethical preference is for a close relative or friend – "the patient's spouse, a son or daughter, a parent, a brother or sister, or a concerned friend . . . ." *Ibid.* Family members, especially, will "usually be most knowledgeable about the patient's goals, preferences, and values." President's Commission report, *supra*, at 128. That is why Florida law prescribes a hierarchy of preferred surrogates which places close relatives and friends at the top of the list and strangers at the bottom. *See* § 765.401(1), Fla. Stat. (2004). Only where no close relative or friend is available should less-satisfactory alternatives be considered. These might include a public guardian, a state-employed ombudsman, or

a "surrogate's committee" created by an "institution, community agency, or other concerned provider organization." Hastings Center Guidelines, *supra*, at 25.

Some bioethicists contend that a surrogate who is not a close relative or friend "should have more limited discretion than a family or friend surrogate and perhaps should be subject to closer review. No wide agreement exists on this, however, or on the standards and mechanisms that would be used to further confine the discretion of a 'stranger surrogate.'" *Id.* at 26. At the very least, however, the stranger surrogate should "be held to the standards applied to family or friend surrogates . . . ." *Ibid.* That is why the judge vested with power to make health-care decisions on behalf of Terri Schiavo was charged with the same responsibility as a family or friend surrogate – to "make a decision that the clear and convincing evidence shows the ward would have made for herself." *Schiavo IV*, 851 So. 2d at 187.

It is difficult enough for a judge to perform that task. "It may be unfortunate that when families cannot agree, the best forum we can offer for this private, personal decision is a public courtroom and the best decision-maker we can provide is a judge with no prior knowledge of the ward, but the law currently provides no better solution that adequately protects the interests of promoting the value of life." *Ibid.*

But if it is "unfortunate" when a court must perform that task, it is wholly inappropriate for a Governor to do so by executive fiat. Like the judge, the Governor has "no prior knowledge of the ward." *Ibid.* Unlike the judge, however, the Governor

has no reliable legal framework available to him for determining the wishes of the patient – no fact-finding mechanisms, no rules of evidence, and no guiding burden of proof. And, indeed, here the Governor made no pretense of even attempting to determine Terri Schiavo's wishes, having summarily ordered the reinsertion of her feeding tube within hours of obtaining the purported authority to do so. As a political leader, the Governor's natural focus is not on Terri's wishes, but on what "the state . . . or public opinion would prefer." *Browning*, 568 So. 2d at 13. That is not the proper focus of surrogate decision-making. *See ibid.*

By authorizing the Governor to make health-care decisions as Terri's proxy, Ch. 2003-418 wrongly trumps the bioethical and legal hierarchy of preferred proxies, placing the authority to make a substituted judgment decision for Terri in the hands of a stranger who knows nothing of her preferences and values. That is anathema to the bioethical principles underlying the law of surrogate decision-making.

II. CHAPTER 2003-418 VIOLATES BIOETHICS BY USURPING A SUBSTITUTED JUDGMENT DECISION WITH A POLITICAL DECISION IN DISREGARD OF TERRI SCHIAVO'S WISHES.

The only requirements prescribed by Ch. 2003-418 for the Governor's exercise of authority to order the reinsertion of Terri Schiavo's feeding tube are that she has no written advance directive, the court has found her to be in a persistent vegetative state,

she has had nutrition and hydration withheld, and a member of her family has challenged the withholding of nutrition and hydration. Florida Laws 2003, ch. 2003-418, § 1. Conspicuously absent from the bill is any requirement, similar to that in the Florida statute governing proxy decision-making, that the Governor make the health care decision he "reasonably believes the patient would have made under the circumstances." § 765.401(2), Fla. Stat. (2004). Nor does the bill prescribe any standards for determining Terri's wishes.

Ch. 2003-418 has nothing to do with substituted judgment decision-making and everything to do with politics. For Terri, and for her alone, the bill does away with the second bioethical model. Under Ch. 2003-418, the focus is on the wishes of a politician rather than Terri's wishes – which the courts have repeatedly determined, upon clear and convincing evidence, are "to permit a natural death process to take its course." *Schiavo I*, 780 So. 2d at 180. A political model has usurped the bioethical preference for a *substituted judgment* decision based on the patient's known wishes and values. That violates the fundamental tenets of bioethics underlying Florida's law of surrogate and proxy decision-making, as well as "the constitutional equilibrium created by the separation of the legislative power to make general law from the judicial power to apply that law in particular cases . . . ." *Plaut v. Spendthrift Farm, Inc.*, 514 U.S. 211, 224 (1995).

The constitutional separation of powers puts case-specific decision-making, such as proxy exercise of Terri Schiavo's right of personal autonomy, in the hands of judges, who are guided by time-tested rules of evidence and procedure and thus, unlike policy-making legislators and Governors, are properly equipped to adjudicate. Case-by-case adjudication of "such questions of life and death . . . require[s] the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created." *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 435 (Mass. 1977).

By vindicating Terri's right of privacy and the separation of powers, and declaring Ch. 2003-418 to be unconstitutional, this court will put the focus where it belongs – not on a political agenda, but on Terri's wishes, which have been fully and fairly determined in the forum best suited for doing so.

III. THE BIOETHICAL ISSUE IN THIS CASE IS NARROWLY RESTRICTED TO PROXY EXERCISE OF THE RIGHT OF PERSONAL AUTONOMY.

This case implicates a narrow bioethical issue: whether the judicial process is better suited than the political arena for implementing proxy exercise of the right of personal autonomy. The Governor's brief on the merits wrongly seeks to broaden the focus of the bioethical debate, in several ways.

First, the Governor suggests that this case implicates the "futile-care theory" allowing a physician to refuse a request for life-sustaining treatment that the physician deems futile. *See* Appellant's Initial Brief at 37 n. 5. But this case has nothing to do with futility theory. Through her proxy, Terri Schiavo has opposed, not requested, tube feeding. Her physicians are neutral. This case is about Terri's choice, not that of her physicians.

That is why the proxy decision here does not threaten the rights of the elderly and the disabled, as the Governor claims. *See id.* at 37-39. The implicated bioethical issue is not whether elderly or disabled persons can be deprived of wanted treatment, but how to implement their fundamental right to decline life-prolonging measures they would abhor. It is certainly true, as the Governor observes, that "the State has a compelling interest in ensuring that people with disabilities are not deprived of basic human rights," *id.* at 39, but among those basic human rights is the right to refuse medical treatment. The Governor wants to deprive Terri Schiavo of that right, which the judicial process has determined she would want to exercise – a political intrusion that terrifies many of the elderly and disabled on whose behalf the Governor claims to speak.

Disability rights advocates are not all "in solidarity" with the Governor's position, contrary to what the Governor's amici curiae suggest. *See* Brief of Amici Curiae Not Dead Yet et al. at 1. Other prominent disability rights advocates, including

the undersigned amicus curiae Autonomy, Inc. and its members, oppose the Governor's position and have spoken out in support of the rights of the disabled and their surrogates to refuse tube feeding. *See* Autonomy *at* http://www.autonomy-now.org (last visited July 27, 2004) (mission statement of Autonomy, Inc. espousing "the interests of people with disabilities who wish to be able to exercise choices concerning all aspects of their lives, including choices at the end of life").

Next, the Governor invokes the need, in cases of proxy decision-making, to protect physicians from being "manipulated by healthcare surrogates who stand to gain from the death of a ward" and from becoming "dupes of those who would exploit an incompetent patient." Appellant's Initial Brief at 38. But this case does not implicate the need to protect patients from self-interested surrogates, because the proxy decision-maker in this case was the trial court, not Michael Schiavo, who invoked Florida's procedure for judicial proxy decision-making. Where, as here, a judge acts as proxy, there is no danger of self-interested decision-making.

Finally, the Governor suggests that the bioethical landscape may have changed because Terri Schiavo was raised Catholic and the Pope recently opined in a speech that tube feeding is morally obligatory. *See id.* at 48. But from the perspective of the Catholic Health Association of the United States (CHA) and many Catholic theologians, the Pope's speech has not changed anything concerning the centuries-old teachings of the Catholic Church on the care due to patients. *See* Ronald Hamel &

Michael Panicola, *Must We Preserve Life?*, America, Nat'l Catholic Wkly. (Apr. 19-26, 2004) vol. 190, no. 14, at 6-13. The Pope noted in his speech that patients in a persistent vegetative state (PVS), like anyone else, have "the right to basic health care." Address of John Paul II to the Participants in the International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas" (Mar. 20, 2004). The duty toward such patients must be appraised within the broader context of the medical care due to all people. The Catholic teaching on that topic is found in such formal pronouncements as the 1980 Vatican Declaration on Euthanasia and John Paul II's 1995 encyclical "Evangelium Vitae," both of which acknowledge the right of a patient or proxy to decline disproportionately burdensome medical treatment. *See* J. Paris, S.J., *The Catholic Tradition on the Use of Nutrition and Fluids*, Birth, Suffering and Death 189-208 (K. Wildes ed., 1992). For decades, Catholic hospitals in the United States have followed policies allowing the withdrawal of feeding tubes in accordance with these documents. Nothing in the Pope's recent statement has caused the CHA to change its policies with regard to PVS patients. To the contrary, the CHA has announced that, even after the Pope's statement, those policies will "remain[] in effect." *See* News Release, Catholic Health Association of the United States, Statement on the Papal Allocution on Persistent Vegetative State (Apr. 1, 2004).

CONCLUSION

"[T]he liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water." *Cruzan*, 497 U.S. at 289 (O'Connor, J., concurring). The same is true of Florida's constitutional right of privacy. The courts having determined Terri Schiavo's personal decision on clear and convincing evidence, the Governor's attempt to trump that decision infringes her constitutional liberty and privacy interests and should be overturned.

For the foregoing reasons and those stated in the Appellee's Answer Brief, this Court should affirm the judgment of the Circuit Court.

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Respectfully submitted,

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