

“I WANT TO LIVE”: MEDICINE BETRAYED BY IDEOLOGY IN THE POLITICAL DEBATE OVER TERRI SCHIAVO

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The public's view of the political intrusion into the medical care of Theresa Marie Schiavo is well illustrated by two political cartoons. The first, by Tony Auth, reprinted in the *Boston Globe* shortly after Congress passed a law authorizing intervention by the federal courts, pictures a horde of congressmen charging mindlessly out of the Capitol, all dressed as physicians—one carrying a saw, another an I.V. pole—with the caption, “Coming Soon to a Sickbed Near You . . . [t]he United States Congress.”¹ The second, by Tom Toles, published in the *Washington Post* shortly after the results of the autopsy report were released, pictures an elephant being examined by two physicians.² The elephant says, “I don't care *what* the autopsy says! I was right to intervene in the Terri Schiavo case and I'll do it *again* if I get the chance.”³ One physician tells the other, “No hope for recovery.”⁴

Religious faith by definition does not depend on facts, but law and medicine do. Traditional advice to a young litigator is, “When the facts are against you, argue the law; when the law is against you, argue the facts; and when both are against you, scream like hell.”⁵ The case of Terri Schiavo was never about the law—the

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1. Tony Auth, *Cartoon*, *Boston Globe* A11 (Mar. 26, 2005).

2. Tom Toles, *Tom Toles Cartoons*, <http://www.washingtonpost.com/wp-srv/opinion/toles.html?name=Toles&date=20050617> (June 17, 2005).

3. *Id.*

4. *Id.*

5. Fred R. Shapiro, *The Oxford Dictionary of American Legal Quotations* 11–12 (Oxford U. Press 1993) (citing *A Treasury of American Anecdotes* 10 (B.A. Botkin ed., Galahad

law was unchallenged and left unchanged by seven years of litigation, a Florida statute, and a federal statute. Nor was the case really about the medical facts. Terri Schiavo was in a permanent vegetative state—as demonstrated by consistent clinical and laboratory determinations during her life and the massive brain damage found on autopsy.⁶ Courts consistently concluded that if she was ever in such a hopeless condition, she would not want her life medically sustained and she would refuse all treatment, including artificially delivered fluids and nutrition.⁷

Although few outside her friends and family ever knew Theresa Schiavo (or her husband, Michael), almost everyone who has commented on her case, or tried to use it for personal or political gain, called her simply “Terri.” This fake familiarity seems to be the inevitable fate that comes with the territory of becoming a symbol in a political battle. Almost everyone with a cause seems to have believed that he or she was competent to speak on her behalf. But outside the judicial system, the case of Terri Schiavo was never really about her, her medical condition, her medical care, or her personal wishes. Her case, instead, was mostly about the screaming from the fundamentalist religious right into the ears of the Governor of Florida; his brother, the President of the United States; the Majority Leader of the United States Senate; and the leaders of the United States House of Representatives. The screams intensified in the filibuster debate and are likely to hit a crescendo with the debate on who will succeed Justice Sandra Day O’Connor, the Supreme Court’s first female Justice and the deciding vote on many critical cases, including *Cruzan*,⁸ the so-called “partial birth abortion” case,⁹ and the case that decided

Books 1957)). The quote reads as follows:

The old lawyer said, “If the evidence is against you, talk about the law. If the law is against you, talk about the evidence.”

The young lawyer asked, “But what do you do when both the law and the evidence are against you?”

“In that case,” replied the old lawyer, “give somebody hell. That’ll distract the judge and the jury from the weakness of your case.”

Id.

6. Wikipedia, *Terri Schiavo, Brief Overview of 15-Year History*, http://en.wikipedia.org/wiki/Terri_Schiavo (last updated Aug. 13, 2005).

7. *Id.*

8. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 262 (1990).

9. *Stenberg v. Carhart*, 530 U.S. 914 (2000).

the election of the current president.¹⁰ What the name Terri Schiavo ultimately stands for in United States and Florida politics remains to be seen. But during the last months of her life she became, at least to the politically active religious right, a symbol of an American judiciary out of control that was making anti-majoritarian decisions on its core social issues, especially abortion, same-sex marriage, and the separation of church and state.¹¹

Although I have been writing about right-to-refuse-treatment cases since the 1976 Karen Ann Quinlan case, I did not focus on the *Schiavo* case until I was invited to participate in the conference at Stetson University College of Law in January 2005, which was the basis for this issue. Following the conference, I decided to write about the case for my "Legal Issues in Medicine" feature in the *New England Journal of Medicine*. My plan was to summarize the existing law, and to reassure my physician readers that no matter what they might have heard to the contrary, the *Schiavo* case did not change the existing law, and they should not alter their medical practices because of it. Instead, on Palm Sunday, to a chorus of religious platitudes about upholding the "culture of life," Congress passed a bill "[f]or the relief of the parents of Theresa Marie Schiavo."¹²

The following day, as United States District Court Judge James Whittemore was hearing arguments about granting a temporary restraining order, I rewrote my article to reflect the congressional action. And on the next day, March 22, the same day Judge Whittemore issued his precise and persuasive opinion, the *New England Journal of Medicine* released my article electronically.¹³ The case of Terri Schiavo had almost instantly gone from

10. *Bush v. Gore*, 531 U.S. 98 (2000). The nomination of Judge Samuel A. Alito, Jr., to replace Justice O'Connor sets up this ideological confrontation. See e.g. Elisabeth Bumiller & Carl Hulse, *Bush Picks U.S. Appeals Judge to Take O'Connor's Court Seat: Hailed by Right*, N.Y. Times A1 (Nov. 1, 2005) (describing the potential for a heated showdown between liberals and conservatives over Alito's nomination); Jeanne Cummings & Jess Bravin, *New Round: Choice of Alito for High Court Sets Stage for Ideological Battle*, Wall St. J. A1 (Nov. 1, 2005) (same).

11. See Jason DeParle, *In Battle to Pick Next Justice, Right Says Avoid a Kennedy*, N.Y. Times A1 (June 27, 2005) ("The confrontation [to pick a new Justice] is coming with a vengeance," wrote Dr. James C. Dobson, in a Focus on the Family Action letter to about two million supporters. As he often does, Dr. Dobson labeled Justice Kennedy 'the most dangerous man in America.'").

12. Pub. L. No. 109-3, § 686, 119 Stat. 15, 15 (2005).

13. The piece appeared in print in an issue of the *Journal* published on April 21, 2005.

one of only local interest, to one potentially affecting physicians and their patients around the country.¹⁴ In this Article, I concen-

George J. Annas, "Culture of Life" Politics at the Bedside: The Case of Terri Schiavo, 352 New Eng. J. Med. 1710 (2005). Portions of the instant article elaborate on the piece previously published in the *New England Journal of Medicine*.

14. The constitutional law on the right to refuse any medical treatment, including life-sustaining treatment, is based primarily on two landmark cases, both of which also dealt with young women in persistent vegetative states (more accurately termed "permanent vegetative states" after twelve months). Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State—Second of Two Parts*, 330 New Eng. J. Med. 1572, 1577 (1995). Like Terri Schiavo, the 1976 case of Karen Quinlan made international headlines when Ms. Quinlan's parents sought the assistance of a judge to have their daughter, who was in a persistent vegetative state, removed from a ventilator. *In re Quinlan*, 355 A.2d 651, 653 (N.J. 1976). Ms. Quinlan's physicians had refused her parents' request to remove the ventilator because, they said, they feared that they might be held civilly or even criminally liable for her death. *Id.* at 651, 669. The New Jersey Supreme Court ruled that competent individuals had a right to refuse life-sustaining treatment and that this right should not be lost when a person becomes incompetent. *Id.* at 662–664. The Court believed the physicians were unwilling to discontinue use of the ventilator because of the fear of legal liability, not precepts of medical ethics; therefore, the Court devised a mechanism to grant the physicians prospective legal immunity for removing the ventilator. *Id.* at 671. Specifically, the New Jersey Supreme Court ruled that after a prognosis that there is "no reasonable possibility of a patient returning to a cognitive, sapient state," and after this prognosis is confirmed by a hospital "ethics committee," life-sustaining treatment can be removed and no one involved, including the physicians, can be held civilly or criminally responsible for the death. *Id.* The publicity surrounding the *Quinlan* case energized two independent developments: it encouraged states to enact "living will" legislation that provided legal immunity to physicians who honored the written "advance directives" specifying how their patients would want to be treated if they ever became incompetent, and it encouraged hospitals to establish "ethics committees" as fora to attempt to resolve similar treatment disputes without going to court.

Although *Quinlan* was widely followed, the New Jersey Supreme Court could make law only for New Jersey. When the United States Supreme Court decided the case of Nancy Cruzan in 1990, it made constitutional law for the entire country. *Cruzan*, 497 U.S. 262. Nancy Cruzan was a young woman in a permanent vegetative state caused by an accident, essentially in identical physical circumstances as Karen Quinlan, except that she was not on a ventilator and, like Terri Schiavo, only needed a feeding tube to continue to live. *Id.* at 462–463. The Missouri Supreme Court ruled that the tube feeding could be discontinued based on Nancy's right of self-determination, but that only Nancy herself should be able to make this decision. If others, including her parents, alleged that she would refuse tube feeding if she could speak for herself, the tube feeding could be stopped only if those speaking for her could demonstrate her wishes by "clear and convincing . . . evidence." *Cruzan v. Harmon*, 760 S.W.2d 408, 425 (Mo. 1988).

The United States Supreme Court, in a five-to-four decision, agreed, saying that the state of Missouri had the authority to adopt this high level of evidence (although no state was required to) because of the finality of a decision to terminate treatment. In the words of the Chief Justice Rehnquist, Missouri was entitled to "err on the side of life." *Cruzan*, 497 U.S. at 265. Judge Greer used this high "clear and convincing evidence" standard in finding that Terri Schiavo herself would refuse continued tube feeding if she was in a permanent vegetative state. Wikipedia, *supra* n. 6. In *Cruzan*, six of the nine Justices explicitly found that there was no legal distinction to be made between artificially delivered fluids and nutrition and other medical interventions, such as ventilator support, and

trate on the forces of the religious right that provoked legislation at both the state and federal level with a view toward learning something about the current state of American medical politics, and the role physician-legislators played in the legislative process.

I. "CULTURE OF LIFE" POLITICS

On Palm Sunday, in a remarkable and unprecedented legislative event, Congress met in a special emergency session to pass legislation aimed at the medical care of one patient: Terri Schiavo.¹⁵ President George W. Bush encouraged the legislation, flying back to Washington, D.C., from his vacation in Crawford, Texas, to be on hand, so he could sign the legislation immediately.¹⁶ In a statement three days earlier he said,

none of the other three found a constitutionally relevant distinction. *Cruzan*, 497 U.S. at 279, 286, 298. This issue is not controversial as a matter of constitutional law: Americans have (and always have had) the legal right to refuse any medical intervention, including artificially delivered fluids and nutrition.

Justice Sandra Day O'Connor recognized, in a concurring opinion (her vote decided the case), that young people do not generally write down explicit treatment instructions. *Id.* at 289 (O'Connor, J., concurring). She suggested that had Nancy simply said something like, "if I'm not able to make medical treatment decisions myself, I want my mother to make them," this should be a constitutionally protected delegation of authority to decide about her treatment. *Id.* at 290. Justice O'Connor's opinion is why the *Cruzan* case energized the healthcare-proxy and durable-power-of-attorney movements—encouraging people to use these documents to designate someone (usually called a healthcare agent, or simply an agent) to make decisions for them if they are not able to make decisions themselves. All states authorize this, and most states explicitly grant decisionmaking authority to a close relative, almost always the spouse first in line, if the patient has not made a designation him or herself.

The law has been remarkably stable since *Quinlan* (which itself restated existing law): competent adults have the right to refuse any medical treatment, including life-sustaining treatment (which includes artificially delivered fluids and nutrition). Incompetent adults retain an interest in self-determination. Competent adults can execute an advance directive stating their wishes and designate an individual to act on their behalf, and physicians can honor these wishes. Physicians and healthcare agents should make treatment decisions consistent with what they believe the patient would want (using the subjective standard), and if the patient's desires cannot be ascertained, then treatment decisions are to be based on the patient's best interests (what a reasonable patient would most likely want in the same circumstances of the patient). This has, I believe, always been the law in the United States. See e.g. George J. Annas, *The Rights of Hospital Patients: The Basic ACLU Guide to a Hospital Patient's Rights* (Norman Dorsen & Aryeh Neier eds., Avon Books 1975) (summarizing a patient's right to refuse treatment).

15. Wikipedia, *supra* n. 6.

16. *Id.*

The case of Terri Schiavo raises complex issues. . . . Those who live at the mercy of others deserve our special care and concern. It should be our goal as a nation to build a culture of life, where all Americans are valued, welcomed, and protected—and that culture of life must extend to individuals with disabilities.¹⁷

The “culture of life” is, of course, a thinly coded reference to the anti-abortion movement (sometimes called the “pro-life movement”), but also can include opposition to physician-assisted suicide, capital punishment, opposition to embryonic stem cell research, and even opposition to war. In the United States, however, it is primarily anti-abortion, anti-embryo research, and anti-same-sex marriage. This movement has never taken issues like universal health insurance or access to medical care seriously and has had virtually nothing to say about cutting Medicaid benefits for millions. On the other hand, the Catholic Church has been consistent, and opposed the Iraq war and capital punishment, and supported healthcare access for all.¹⁸ Although the rhetoric suggests that its opposite is a “culture of death” (a phrase popularized by Pope John Paul II),¹⁹ the legal and political mirror image is more properly seen as a “culture of liberty”—where individuals are free to make their own deeply personal decisions free from government coercion, including decisions about pregnancy, medical care, and marriage. In President Bush’s first term, the religious right seemed to focus primarily on passing a blatantly unconstitutional “partial birth abortion” ban,²⁰ strictly limiting fed-

17. U.S. Govt., *White House, President’s Statement on Terri Schiavo*, <http://www.whitehouse.gov/news/release/2005/03/print/20050317-7.html> (Mar. 17, 2005). The President’s interruption of his vacation to return to Washington to sign the legislation was not necessary (it could have been delivered to him for signature), but seems to have been done primarily to please his extreme-right-wing, evangelical Christian base. Richard Cizik, Vice President of the National Association of Evangelicals, said signing the bill in Crawford, Texas, “would have been acceptable. . . . But this president seizes opportunities when they come his way. That’s what makes him a good politician.” Elisabeth Bumiller, *The Schiavo Case: The President; Supporters Praise Bush’s Swift Return to Washington*, N.Y. Times A15 (Mar. 21, 2005).

18. Nancy Frazier O’Brien, *Campaign ’04: Candidates Back Church Call for Health Care Reform*, <http://www.catholicnews.com/data/stories/cns/0403348.htm> (June 17, 2004).

19. Br. Scott Murphy, *Pope Benedict XVI and a Deadly Dictator*, http://www.catholic.net/the_pope_page/template_channel.phtml?channel_id=18 (accessed Aug. 16, 2005).

20. It is worth noting that this law (even if constitutional) would not prevent even one abortion, and thus not “save” even one fetus, and was passed almost totally as a symbolic

eral funding for human embryonic stem cell research, and opposing state court decisions giving same-sex marriage constitutionally protected status.²¹

After last fall's election, the religious right saw itself as significantly strengthened and, among other things, decided to reopen the lost debate of the 1980s concerning whether artificially delivered fluids and nutrition should be classified as a medical treatment like any other, or should be seen as unique, and always obligatory, at least for incompetent patients. The *Schiavo* case seemed a good vehicle. But did the election of 2004 so change American politics and American bioethics that faith-based legislation is now seen by a majority of the country as an appropriate response to judicial opinions that the religious right finds offensive?

II. THE FLORIDA LEGISLATURE

Like the 2000 presidential election itself, the politicization of the *Schiavo* case began in Florida. Following the court-ordered removal of the feeding tube from Terri Schiavo in October 2003, and after intense lobbying by organized "right-to-life" groups, the Florida Legislature passed a new law, often referred to simply as "Terri's Law," which gave Governor Jeb Bush the authority to order the feeding tube reinserted, and he did so.²² The law applied only to a patient who met the following criteria on October 15, 2003, i.e., only to Terri Schiavo—a patient who

- (a) . . . has no written advance directive;
- (b) [a] court has found . . . to be in a persistent vegetative state;
- (c) . . . has had nutrition and hydration withheld; and

political gesture to the anti-abortion movement. See George J. Annas, "Partial Birth Abortion" and the Supreme Court, 344 *New Eng. J. Med.* 152 (2001); George J. Annas, *Partial Birth Abortion, Congress, and the Constitution*, 339 *New Eng. J. Med.* 122 (1998).

21. David D. Kirkpatrick, *Some Bush Supporters Say They Anticipate a 'Revolution'*, <http://www.commondreams.org/cgi-bin/print.cgi?file=/headlines04/1104-04.htm> (accessed Aug. 13, 2005).

22. 2003 Fla. Laws ch. 418; Wikipedia, *supra* n. 6.

(d) . . . has [a family member that had] challenged the withholding of nutrition and hydration.²³

The constitutionality of this law was immediately challenged.²⁴ In the fall of 2004, the Florida Supreme Court ruled that the law was unconstitutional because it violated the separation of powers—the division of the government into three branches, each with its own powers and responsibilities: the executive, the legislative, and the judicial.²⁵ The doctrine states simply that “no branch may encroach upon the powers of another” branch and “no branch may delegate to another branch its constitutionally assigned power.”²⁶ Specifically, the Court held that for the legislature to pass a law that permits the executive to “interfere with the final judicial determination in a case” is “without question an invasion of the authority of the judicial branch.”²⁷ The Court also found the law unconstitutional for an independent reason, because it “delegates legislative power to the Governor” by giving the Governor “unbridled discretion” to make a decision about a citizen’s constitutional rights.²⁸ In the Court’s words,

If the Legislature with the assent of the Governor can do what was attempted here, the judicial branch would be subordinated to the final directive of the other branches. Also subordinated would be the rights of individuals, including the well established privacy right to self determination. . . . Vested rights could be stripped away based on popular clamor.²⁹

In January 2005, the United States Supreme Court refused to hear an appeal brought by Governor Bush.³⁰ Thereafter, the state trial court judge ordered that Schiavo’s feeding tube be removed in thirty days (at 1:00 p.m., Friday, March 18), unless a higher

23. 2003 Fla. Laws ch. 418.

24. *Schiavo v. Bush*, 2004 WL 980028 (Fla. Cir. Ct. 6th Dist. May 5, 2004).

25. *Bush v. Schiavo*, 885 So. 2d 321, 324, 329 (Fla. 2004).

26. *Id.* at 329 (quoting *Chiles v. Children A, B, C, D, E, & F*, 589 So. 2d 260, 264 (Fla. 1991)).

27. *Id.* at 332.

28. *Id.*

29. *Id.* at 337.

30. *Bush v. Schiavo*, 125 S. Ct. 1086 (2005).

court again intervened.³¹ After this decision, the judge, George W. Greer of the Pinellas County Circuit Court, was picketed, threatened with death, and had to be accompanied by armed guards at all times.³² Schiavo's parents, again with the aid of a variety of religious fundamentalist and "right-to-life" organizations, sought review in the appeals courts, a new statute in the state legislature, and finally, congressional intervention.³³ Both the trial and appellate courts refused to reopen the case based on claims of new evidence, including the Pope's 2004 statement on fluids and nutrition, and the failure to appoint an independent lawyer for her at the original hearing.

In Florida, the Legislature considered, and the House passed, new legislation aimed at restoring the feeding tube, but the Florida Senate, recognizing, I think, that this new legislation, like the 2004 law, would be unconstitutional for the same reason, ultimately refused to go along. Searching for another way to proceed, Ken Connor, a prominent Florida trial attorney and Christian conservative who had represented Governor Bush on this issue, turned to his friend, physician and Congressman Dave Weldon, to try to devise a way for Congress to demand that the federal courts intervene.³⁴ House Majority Leader Tom DeLay, who was under intense attack for alleged ethics violations, was only too happy to oblige.³⁵ As he told a conference organized by the Family Research Council, a conservative Christian group in Washington, D.C., on Friday, March 19, "One thing that God has brought to us is Terri Schiavo, to help elevate the visibility of what is going on in America. . . . This is exactly the issue that is going on in America, of attacks against the conservative movement, against me and against many others."³⁶ Congress decided that a winning argument would be that Terri Schiavo deserved at least as much due process from the federal courts as a convicted murderer facing

31. Or. to Remove Theresa Schiavo's Nutrition & Hydration, *In re Guardianship of Schiavo* 3 (Fla. Cir. Ct. 6th Dist. Feb. 25, 2005) (available at <http://www.miami.edu/ethics2/schiavo/timeline.htm>).

32. Julia Duin, *Judge in Schiavo Case Faces Death Threat*, Wash. Times A1 (Mar. 30, 2005).

33. Wikipedia, *supra* n. 6.

34. David D. Kirkpatrick & Sheryl Gay Stolberg, *The Schiavo Case: The Campaign; How Family's Cause Reached the Halls of Congress*, N.Y. Times A1 (Mar. 22, 2005).

35. *Id.*

36. *Id.*

execution.³⁷ Thereupon an event unique in American politics occurred: after more than a week of discussion, and after formally declaring their Easter recess without action, Congress reconvened two days after the feeding tube was removed to consider emergency legislation designed to apply only to Terri Schiavo.

III. CONGRESS AT THE BEDSIDE

Under rules that permitted a few senators to act if no senator objected, the United States Senate adopted a bill titled, “For the Relief of the Parents of Theresa Marie Schiavo” on March 21, 2005,³⁸ with only three senators present: Majority Leader Bill Frist, Senator John Warner of Virginia, and Senator Mel Martinez of Florida.³⁹ In doing so, a private family dispute that the courts had resolved transformed into a national medical-science-versus-fundamentalist-religion dispute. On March 17, 2005, Frist, a former heart transplant surgeon (who insists on being called “Dr. Frist” even though his current occupation is Senate Majority Leader) said,

When I first heard about the situation facing Terri Schiavo, I immediately wanted to know more about the case from a medical standpoint. I asked myself, just looking at the newspaper reports, *is Terri clearly in this diagnosis called a persistent vegetative state?*

I was interested in it in part because it is a very difficult diagnosis to make and I've been in a situation such as this many, many times before as a transplant surgeon. . . . *Persistent vegetative state, which is what the court has ruled—I question it. I question it based on a review of the video footage which I spent an hour or so looking at last night in my office here in the Capitol. And that footage, to me, depicts something very different than persistent vegetative state. . . . I mentioned that Terri's brother told me that Terri laughs,*

37. See 151 Cong. Rec. H1715 (daily ed. Mar. 20, 2005) (reasoning that because the Constitution allowed Scott Peterson and John Couey (a man who admitted killing a child in Florida) a federal review of their cases, Terri Schiavo was entitled to the same amount of federal review). *Id.*

38. 151 Cong. Rec. at H1700–1708.

39. Kathy Gill, *Roll Call Vote, Terri Schiavo Act*, http://uspolitics.about.com/od/electionissues/a/sb686_vote_p.htm (accessed Aug. 18, 2005).

smiles, and tries to speak. Doesn't sound like a woman in a persistent vegetative state.

[T]here just seems to be insufficient information to conclude that Terri Schiavo is in a persistent vegetative state[.] [S]ecuring the facts I believe is the first and proper step at this juncture.⁴⁰

Any senator could have stopped the madness with an objection—but none did.⁴¹ Apparently Republican senators were willing to go along with their leader—a physician whom they trusted on medical issues. Democrats were rudderless and afraid. They were afraid of being labeled the party of death—and more concretely afraid of potentially hurting Florida Senator Bill Nelson's reelection chances. Nelson had refused to sign on as a sponsor of the bill.⁴² The contemporary view of the political implications of the bill was summarized in a memorandum written (it was later learned) by the legal counsel of Senator Mel Martinez (known by some in Florida as Senator Bush “because of his eagerness to please his political masters”).⁴³ The memo, which Martinez helped circulate, characterized the *Schiavo* case as “a great political issue” for Republicans and “a tough issue for Democrats,” especially Bill Nelson, who could be portrayed as Terri Schiavo's Democrat Angel of Death.⁴⁴ Because of the lack of courage or conviction in the Senate, the real legislative action was in the House of Representatives, where many physician-members were eager to join Dr. Frist in his video medical consultation.

The House, under whose rules a majority of its members had to be present to vote, debated the same measure from 9:00 p.m. to

40. Bill Frist, *Speeches, Statement on Terri Schiavo Bill, Floor Statement*, http://frist.senate.gov/index.cfm?FuseAction=speeches.Detail&Speech_id=174 (Mar. 17, 2005) (emphasis added).

41. 151 Cong. Rec. at H1725.

42. *Id.*

43. Mike Allen, *Counsel to GOP Senator Wrote Memo on Schiavo*, Wash. Post A1 (Apr. 7, 2005); Memo. from Brian H. Darling, Legal Counsel to Sen. Mel Martinez, to Sen. Mel Martinez, U.S. Sen., R-Fla., *The Incapacitated Person's Legal Protection Act* (Mar. 18, 2005) (copy on file with the *Stetson Law Review*).

44. Philip Gailey, *A Lack of Brain Activity in Congress*, St. Petersburg Times 3P (Mar. 20, 2005); Daniel Ruth, *The Best Part? Sen. Mel's Term Is Just Starting*, Tampa Trib. 2 (Apr. 11, 2005). (Martinez has since said he did not know who wrote the memo at the time—his legal counsel Brian Darling—or that he himself had given it to Senator Tom Harkin.)

midnight on Palm Sunday, and passed it by a four-to-one margin (203 to 58) shortly after midnight on Monday, March 21. In substance, the new law, which was to set no precedent, provided that “[t]he District Court for the Middle District of Florida shall have jurisdiction to hear . . . a suit . . . for the alleged violation of any right of Theresa Marie Schiavo under the Constitution or laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life.”⁴⁵ The parents had standing to bring the lawsuit, and the court was instructed to “determine de novo any claim of a violation of any right of Theresa Marie Schiavo . . . notwithstanding any prior State court determination.”⁴⁶

45. Pub. L. No. 109-3, § 686, 119 Stat. 15, 15 (2005).

46. *Id.* The full text of the law is

SEC. 1. RELIEF OF THE PARENTS OF
THERESA MARIE SCHIAVO.

The United States District Court for the Middle District of Florida shall have jurisdiction to hear, determine, and render judgment on a suit or claim by or on behalf of Theresa Marie Schiavo for the alleged violation of any right of Theresa Marie Schiavo under the Constitution or laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life.

SEC. 2. PROCEDURE.

Any parent of Theresa Marie Schiavo shall have standing to bring a suit under this Act. The suit may be brought against any other person who was a party to State court proceedings relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain the life of Theresa Marie Schiavo, or who may act pursuant to a State court order authorizing or directing the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life. In such a suit, the District Court shall determine de novo any claim of a violation of any right of Theresa Marie Schiavo within the scope of this Act, notwithstanding any prior State court determination and regardless of whether such a claim has previously been raised, considered, or decided in State court proceedings. The District Court shall entertain and determine the suit without any delay or abstention in favor of State court proceedings, and regardless of whether remedies available in the State courts have been exhausted.

SEC. 3. RELIEF.

After a determination of the merits of a suit brought under this Act, the District Court shall issue such declaratory and injunctive relief as may be necessary to protect the rights of Theresa Marie Schiavo under the Constitution and laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life.

SEC. 4. TIME FOR FILING.

Notwithstanding any other time limitation, any suit or claim under this Act shall be timely if filed within 30 days after the enactment of this Act.

The brief debate on this bill in the House of Representatives—there were no hearings in either chamber, and no debate at all in the United States Senate—was notable primarily for its incredibly uninformed and frenzied rhetoric and was covered live by C-SPAN. The primary sponsor of the measure, Tom DeLay, for example, asserted, “She’s not a vegetable, just handicapped like many millions of people walking around today. This has nothing to do with politics, and [it’s] disgusting for people to say that it does.”⁴⁷ Others echoed the sentiments of Senator Bill Frist, who had added earlier that day that immediate action by Congress was imperative because “Terri Schiavo is being denied life-saving fluids and nutrition as we speak.”⁴⁸

SEC. 5. NO CHANGE OF SUBSTANTIVE RIGHTS.

Nothing in this Act shall be construed to create substantive rights not otherwise secured by the Constitution and laws of the United States or of the several States.

SEC. 6. NO EFFECT ON ASSISTING SUICIDE.

Nothing in this Act shall be construed to confer additional jurisdiction on any court to consider any claim related-

- (1) to assisting suicide, or
- (2) a State law regarding assisting suicide.

SEC. 7. NO PRECEDENT FOR FUTURE LEGISLATION.

Nothing in this Act shall constitute a precedent with respect to future legislation, including the provision of private relief bills.

SEC. 8. NO EFFECT ON THE PATIENT SELF-DETERMINATION ACT OF 1990.

Nothing in this Act shall affect the rights of any person under the Patient Self-Determination Act of 1990.

SEC. 9. SENSE OF THE CONGRESS.

It is the Sense of Congress that the 109th Congress should consider policies regarding the status and legal rights of incapacitated individuals who are incapable of making decisions concerning the provision, withholding, or withdrawal of foods, fluid, or medical care.

Id.

47. DeLay added during the brief floor debate,

I say again, the legal and political issues may be complicated, but the moral ones are not. A young woman in Florida is being dehydrated and starved to death. For 58 long hours, her mouth has been parched and her hunger pangs have been throbbing. If we do not act, she will die of thirst. However helpless, Mr. Speaker, she is alive. She is still one of us. And this cannot stand. Terri Schiavo survived her Passion weekend, and she has not been forsaken. No more words, Mr. Speaker. She is waiting. The Members are here. The hour has come.

151 Cong. Rec. at H1725.

48. Congressman James Sensenbrenner, who led the floor debate for the Republicans, echoed Frist’s sentiments and added a distinctly religious tone in his opening remarks on

Almost all of the physician members of the House chimed in,⁴⁹ and their statements are worth recording in some detail because almost all of them turned their backs on the medical facts of the case and pandered instead to religiously inspired political passion. In the order in which they spoke, Congressman Phil Gingrey, whose website features him as “Phil Gingrey, M.D.” and on which he describes himself “[a]s a pro-life OB-GYN,” saying “[my] 100% pro-life voting record reflects . . . my commitment to support life at every stage,” was first.⁵⁰ He said,

I am not playing doctor, for indeed I am one . . . since Terri Schiavo’s brain injury 15 years ago, she has been profoundly disabled. She is not, however, in a coma. *She responds to people around her; she smiles and she can feel. Terri is very much alive. . . . Terri’s condition can improve.* Terri responds to verbal, auditory, and visual stimuli, normally breathes on her own and can move her limbs on command . . . to uphold a culture of life and compassion it is important we act today to save Terri Schiavo’s life and uphold the moral and legal obligation of our nation, indeed this poor woman’s Constitutional right to life.⁵¹

Congressman Dave Weldon, who should take credit for getting the measure before Congress in the first place, remarked,

I practiced medicine for 15 years, internal medicine, before I came to the House of Representatives. I took care of a lot of these kinds of cases. . . . *Number one, by my medical definition she was not in a vegetative state based on my review of the videos, my talking to the family, and my discussing the*

the floor, “As millions of Americans observe the beginning of Holy Week this Palm Sunday, we are reminded that every life has purpose, and none is without meaning. The battle to defend the preciousness of every life in a culture that respects and defends life is not only Terri’s fight, but it is America’s fight.” *Id.* at H1701.

49. *See id.* at H1700–H1728 (collecting comments from members of the House).

50. Phil Gingrey, *Issues, Pro-Life*, <http://gingrey.house.gov/Issues/Issue/?IssueID=1590> (accessed Aug. 18, 2005).

51. 151 Cong. Rec. at H1712–1713 (emphasis added). Gingrey also said, “Florida law prohibits the starvation of dogs, yet will allow the starvation of Terri Schiavo. . . . Although I am not a neurologist by specialty, my basic courses in medical school taught me that dehydration is a horrific process.” *Id.*

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case with one of the neurologists who examined her. And, yes, I asked to get into the room and was unable to do so."⁵²

Another physician-Congressman, Tom Price, was more thoughtful and simply said that he thought the law was reasonable because there was "no living will in place" and the family and experts disagreed.⁵³ Physician-Congressman Jon Schwarz, a head and neck surgeon, said,

I shall not try to influence the opinion of anyone on this issue. I will simply share with you my opinion, the opinion of a physician of almost 41 years' duration. . . . Terri Schiavo has spontaneous respiratory activities and respontaneous cardiac activity. *She is not on life support*, as we routinely define it. She is not intubated and she is not on a respirator . . . *she does have some cognition and some cortical activity*. Removing her gastrostomy tube will ultimately cause her demise. . . . How many others in this country are now in long-term care facilities with feeding tubes, but . . . breathe on their own, their hearts beating strongly? Should their feeding tubes be removed as well? I think not.⁵⁴

Finally, Congressman Charles Boustany's remarks were recorded, even though his flight to Washington was delayed and he was not able to deliver them personally:

As a physician, I have been faced with many families in situations similar to that of Terri Schiavo's family. . . . But fortunately, *advances in medical technology have made recovery possible when before it was not possible*. I have seen people recover from illnesses to lead fulfilling lives when most thought all hope was lost. But Terri Schiavo's parents have not lost hope. . . . Her parents only ask that they be al-

52. *Id.* at H1715 (emphasis added). Weldon also questioned Michael Schiavo's veracity based on his medical experience: "My clinical experience has always been that immediately family brings that up [the patient's stated wishes regarding life-sustaining treatment]. They do not wait 7 years." *Id.*

53. *Id.* at H1716. Price, to his credit, did not try to make a diagnosis; instead he said he prayed about the case: "As I sat in church this morning, I struggled with this and I prayed. I prayed for a lowering of the rhetoric. I prayed for a decrease in the emotion." *Id.*

54. *Id.* at H1717 (emphasis added).

lowed to care for her. How can we deny her parents that possibility?⁵⁵

The only physician troubled by the public, long-distance diagnosis of Schiavo by Congress was psychiatrist-Congressman James McDermott, who chided his physician colleagues for making a diagnosis without examining the patient, noting that this was bad practice:

And what troubles me, and I have heard my colleagues here, as a psychiatrist, I cannot make diagnoses of people I have not examined. That is contrary to my profession, and I can be disciplined for doing that. *The rest of you can be doctors. You can come out here and tell us anything you want. But a doctor cannot come out here and say anything really about somebody [he or she has] not examined.*⁵⁶

While deferring to the medical expertise of his congressional colleagues with medical degrees, Congressman Barney Frank, who vigorously led the floor fight for those opposed to the measure (most, but not all, of whom were Democrats), recognizing that the chamber was not filled with physicians, quipped, “We’re not doctors, we just play them on C-SPAN.”⁵⁷ The major slogans that recurred in the debate were that in a life-or-death decision we should “err on the side of life,” that action should be taken to prevent “death by starvation” and ensure the “right to live,” and that Congress should “protect the rights of disabled people” and give them at least the same rights to federal judicial review that convicted criminals have.⁵⁸

55. *Id.* at H1727 (emphasis added).

56. *Id.* at H1718 (emphasis added).

57. *Id.* at H1712. Congressman Barney Frank continued, The point is this: The gentleman [Congressman Sensenbrenner] is making specific medical arguments. He has said, in strong criticism of the entire judicial system of the state of Florida, that they did not give her a fair chance; that the entire judicial system, all of those appeals, all of those trials, all of that litigation, that that did not give her a fair chance and we will now vacate the judgment of Florida. And why? Not because any of us know one thing or another, but *because many Members here genuinely have a strong ideological interest*, and that is precisely why this ought to be a judicial decision and not a legislative decision.

Id. (emphasis added). Congressman Frank was their leader, but other members of Congress who were especially eloquent in opposing the measure included Ginny Brown-Waite, John Conyers, Michael Capuano, and Debbie Wasserman Schultz.

58. 151 Cong. Rec. at H1700.

All of these have some abstract truth, but none have much to do with Terri Schiavo herself. No one was starving her—like Nancy Cruzan, she was incapable of eating, and a drug-like substance was being medically delivered to her body by a tube that had been surgically inserted, a continuing invasion of her body that she had a right to refuse.⁵⁹ She was so far beyond “disabled” that the term could not accurately be used to describe her condition. She was permanently unconscious and unable to do anything; her upper brain was not “damaged,” but absent altogether.⁶⁰ Finally, she was not a convicted criminal, and the state was taking no action to execute her; this analogy seems to have been invented to imply that Michael Schiavo had somehow caused Terri’s original injury (and thus disqualified himself to speak on his wife’s behalf), an unsubstantiated charge that Governor Jeb Bush continues to act as if he believes to this day.

Upon reviewing the new law, Judge Whittemore denied a request for a preliminary injunction to have the feeding tube reinserted, finding that the parents had failed to demonstrate “a substantial likelihood of success on the merits.”⁶¹ In his well-reasoned opinion, subsequently affirmed on appeal, he found that the claim that Schiavo had not been accorded due process was unpersuasive because the case had already been “exhaustively litigated,” and throughout, all parties had been represented by able counsel; furthermore, the First Amendment claim that Schiavo’s right to practice her religion was being violated by the state was meritless because there was no state action involved.⁶² Although the issue was never litigated, the statute itself would likely have been found unconstitutional for the same reasons the Florida Supreme Court found Terri’s Law unconstitutional. Fol-

59. *Cruzan*, 497 U.S. at 269–270 (1990).

60. Abby Goodnough, *Schiavo Autopsy Says Brain, Withered, Was Untreatable*, N.Y. Times A1 (June 16, 2005).

61. *Schiavo ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378, 1383 (M.D. Fla. 2005).

62. *Id.* at 1386. Whittemore’s opinion incensed the right-to-life and religious communities. Burke J. Balch of the National Right to Life Committee, for example, said, “Judge Whittemore has engaged in a gross abuse of judicial power.” Carl Hulse & David Kirkpatrick, *Casting Angry Eye on Courts, Conservatives Prime for Bench-Clearing Brawl in Congress*, N.Y. Times A15 (Mar. 23, 2005). Rev. Jerry Falwell said, “Just because there is a judge somewhere in the world who would give an estranged husband like that the time of day tells you how bad the court system is,” and Richard Viguerie, a conservative group direct-mail advisor said, “It could be the opening shot in the Supreme Court nomination battle that we expect sooner rather than later.” *Id.*

lowing Judge Whittemore's opinion, unsuccessful appeals, demonstrations, and almost constant coverage by cable news stations, Terri Schiavo died on March 31.⁶³ Her death, however, did not stop the screaming.

IV. SCREAMING FOR TERRI (OR WHY THE FACTS NEVER MATTERED)

The case of Terri Schiavo's parents was championed by a wide variety of right-to-life groups and fundamentalist religious organizations that politicians like Bill Frist found themselves unable to resist. Nor could members of the public or Congress make a reasoned judgment about the case, based on the blatant misrepresentation of the facts, most notably the release of edited videotapes that seemed to show her interacting with visitors, thus conscious and aware of her surroundings, and able to suffer physically and mentally. The list of conservative lobbyists and special interest groups that sought to use the Schiavo saga to further their agenda is long, but two examples illustrate their tactics.

The first is the conservative website RightMarch.com, whose publicity on the case featured a flyer (which could be printed from their website for distribution) with the headline "Tell Congress to Help Save Terri Schiavo from Starvation."⁶⁴ The flyer included the following "facts" about her medical condition:

Terri laughs, Terri cries, she moves, and she makes child-like attempts at speech with her parents. Sometimes she will say 'Mom' or 'Dad' or 'yeah' when they ask her a question. When they kiss her hello or goodbye, she looks at them and 'puckers up' her lips.⁶⁵

RightMarch was aided in its campaign by the Right Brothers, who agreed to let it use their anti-abortion song, "I Want to Live," for this cause.⁶⁶ Although specifically written for anti-abortion work, the chorus, which includes the refrain, "Mama I want to

63. CNN, *Terri Schiavo's Life, Death Sparked National Debate*, <http://www.cnn.com/2005/us/03/31/obit.schiavo/> (accessed Aug. 28, 2005).

64. RightMarch, <http://rightmarch.com/media/terrislawad.pdf> (accessed Oct. 5, 2005).

65. *Id.*

66. Alison Hoover, *The Right Brothers: The Right Music*, <http://www.tuftsprimarysource.org/issues/23/10/hoover.html> (accessed Aug. 21, 2005).

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live, Mama I want to breathe,”⁶⁷ was apparently seen as close enough for use in the campaign. Of course, like a fetus, Terri Schiavo herself was silent. The assertions that she could communicate, and even say “I want to live,” echoed the medically inaccurate arguments of the anti-abortion film “Silent Scream” (first shown in the mid-1980s), which features an ultrasound film of a twelve-week fetus, who, like Schiavo, is said to be in distress and struggling to survive.⁶⁸

The second example involves more direct action demonstrations and is perhaps best illustrated by a photograph taken on March 18, the day the feeding tube was removed. Outside of the hospice, Reverend Rob Schenck and Reverend Ed Martin posed for photographers by crying in agony as if they had just learned that their only child had been killed (the color photo appeared on the front page of newspapers on March 19, including the Tampa Tribune).⁶⁹ Reverend Schenck works closely with Reverend Patrick Mahoney of Faith and Action, an umbrella religious organization that, among other things, was dedicated to abolishing the filibuster and replacing liberal judges with those who believe as they do that every human being at every stage has dignity no matter what its dependency.⁷⁰

Reverend Mahoney (now director of the Christian Defense Coalition), who was originally a leader of the anti-abortion group Operation Rescue,⁷¹ has said about the fight for the new judicial appointment, “[T]his will be about abortion. Make no mistake

67. The Right Brothers, *I Want to Live* (The Right Brothers) (CD).

68. Silent Scream, *The Silent Scream: Part One–Part Five*, <http://www.silentscream.org/video/1-5.htm> (accessed Aug. 21, 2005); see also Philip Kennicott, *Symbol of Emptiness: Terri Schiavo Was a Woman, Not an Idea*, Wash. Post C1 (Apr. 1, 2005) (explaining how Terri Schiavo became a symbol in an ideological debate). “Schiavo couldn’t speak for herself, and she was hidden from view, in a hospice. This silence, this absence, made her an attractive figure for people [who wanted to use her as a symbol of their cause] to speak for her. . . . [T]he creators of Terri went further. She began saying more than it was quite possible to believe. . . . [S]he even tried to say ‘I want to live,’ according to family members. . . . To believe in this Terri required more and more disbelief in medical science.” See also Editorial, “I Want to Live,” Wall St. J. W11 (Mar. 25, 2005) (questioning whether the legal system presumes people would rather be dead than disabled).

69. David Sommer, *Schiavo’s Feeding Stops*, Tampa Trib. 1 (Mar. 19, 2005).

70. See e.g. *Faith and Action*, <http://www.faithandaction.org>. (accessed Nov. 7, 2005) (promoting religious activism).

71. *Id.*; see also *Family Policy; Abortion Haunts the President*, The Economist 22 (Aug. 17, 1991) (describing the abortion debate in the United States).

about it.”⁷² In 1990, he recounted how he and his colleagues were trying to get media attention outside of Nancy Cruzan’s nursing home after her feeding tube was discontinued by court order on the basis that it was her wish.⁷³ He recalled how they had to beg the night clerk to use the fax machine. “That’s how sophisticated we were. We were desperately trying to get the word out, desperately trying to get people out. There just wasn’t much interest.”⁷⁴ Today he says that by turning to the Internet, alternative media, and grass-roots organizations, what he calls the “faith-and-values community” has “unleashed an avalanche of support for Schiavo’s parents.”⁷⁵

Former Republican Senator and Episcopal minister John C. Danforth got it right when he observed that in pushing the Schiavo legislation, the Republican Party departed from its principles, especially those involving government intrusion into private decisions and federal courts overruling state courts, and “can rightfully be interpreted as yielding to the pressure of religious power blocs.”⁷⁶ Danforth went further, concluding that the Republican Party’s “current fixation on a religious agenda has turned it in the wrong direction.”⁷⁷

V. THE AUTOPSY REPORT

To the extent that the medical facts mattered, the autopsy report on Schiavo settled them. It was released on June 13, 2005.⁷⁸ Although the clinical diagnosis of persistent or permanent vegetative state (PVS) cannot be determined on autopsy, the physical findings were consistent with a PVS.⁷⁹ With specific reference to her brain, the report concluded the following:

72. *Hardball with Chris Matthews* (MSNBC May 24, 2005) (TV broadcast, transcr. available at <http://www.msnbc.msn.com/id/7980441>).

73. Maya Bell, *Sophisticated Tactics Aid Schiavo’s Parents*, Orlando Sentinel A1 (Mar. 13, 2005).

74. *Id.*

75. *Id.*

76. John Danforth, *In the Name of Politics*, N.Y. Times A27 (Mar. 30, 2005).

77. *Id.* Danforth could have noted that Republicans have not been consistent in their anti-state interference with personal decisions since they adopted the anti-abortion agenda of the right-to-life movement and its attempt to make abortion a crime.

78. Jon R. Thogmartin, *Report of Autopsy* (Dist. Six, Pasco & Pinellas Counties June 13, 2005) (available at <http://news.findlaw.com/hdocs/docs/Schiavo/61305autopsyrpt.pfd>).

79. *Id.*

Mrs. Schiavo's brain showed marked global anoxic-ischemic encephalopathy resulting in massive cerebral atrophy. Her brain weight was approximately half of the expected weight. Of particular importance was the hypoxic damage and neuronal loss in her occipital lobes, which indicates cortical blindness. Her remaining brain regions also show severe hypoxic injury and neuronal atrophy/loss.⁸⁰

This confirms that the only functioning part of her brain was her brain stem—she had no upper brain activity and, therefore, no ability to interact with her environment, and certainly no ability to speak.⁸¹ Although her eyes could open, she was incapable of seeing.⁸² The injuries to her brain were irreversible and no beneficial therapy was possible. The ultimate cause of her “severe anoxic brain injury” could not be determined with reasonable medical certainty, and the medical examiner left the case open, as it is the policy of his office “that no case is ever closed and that all determinations are to be reconsidered upon receipt of credible, new information.”⁸³

A week before the autopsy report was released, I had the privilege of participating in a program sponsored by the District of Columbia Bar Association on the *Schiavo* case and its post-Congressional action litigation with two of the appellate litigators, one from each side: Professor Robert Destrow (for the parents) and Attorney Thomas J. Perrelli (for the husband). I gave the first presentation, essentially summarizing the law, and as an

80. *Id.*

81. See Ltr. from Stephen J. Nelson, M.D., Chief Med. Examr. of the 10th Jud. Cir. of Fla., to Jon R. Thogmartin M.D., 6th Jud. Cir. of Fla. Med. Examr., *Neuropathology Report on Theresa Marie Schiavo* 4–5 (June 8, 2005) (copy on file with the *Stetson Law Review*) (commenting that Theresa Schiavo's brain weighed “less than half of the expected tabular weight for a decedent of her adult age”). For a more in-depth description of right wing organizations and think tanks supporting the parents, see Jon B. Eisenberg, *Using Terri: The Religious Right's Conspiracy to Take Away Our Rights* 94–109 (Harper S.F. 2005) (detailing the history and hierarchy behind the organizations that provided crucial funding for the *Schiavo* case). Eisenberg identifies by name and role “[s]even foundations in the high command, fourteen think tanks and other religious Right members of the officer corps, and eighteen foot soldiers behind the Schindlers and Governor Bush in the *Schiavo* case.” *Id.* at 96. Eisenberg also filed an amicus brief on behalf of a group of bioethicists supporting Michael Schiavo in his successful attempt to have the Florida law declared unconstitutional. *Id.* at 126–127. I signed on to that brief.

82. Thogmartin, *supra* n. 78, at 8.

83. See Goodnough, *supra* n. 60, at A1 (describing Theresa Schiavo's autopsy results).

aside on the facts said that if the autopsy report was inconsistent with permanent vegetative state, I would be the first to say I was wrong to rely on the judge's evaluation of the medical testimony. Professor Destrow, on the other hand, made it clear that whatever the autopsy report concluded, it would not affect the opinions of many of those who sided with the parents. In his words, "The autopsy is interesting. But we wanted to know what her living brain could do, not what her dead brain can't do."

Destrow is not the only one trying to deny the medical facts found in the autopsy report. The family of Terri Schiavo, understandably, could not accept the autopsy results.⁸⁴ But other, more politically motivated people tried to use the autopsy results for their own purposes. Governor Bush, for example, has used it to make it appear that he was right to question Michael Schiavo's competence to speak for his wife, by maliciously and without any evidence asking a prosecutor to investigate him to see whether he delayed calling 911 on the night of Terri's heart attack.⁸⁵ As prosecutor Bernie McCabe told a columnist for the *New York Times*, he has no basis for the investigation and agreed to do it only because Jeb Bush asked him to.⁸⁶

William Hammesfahr, one of the two primary medical witnesses for Terri's parents at trial, and whose trial testimony that he could treat Terri Judge Greer discounted as not credible, also

84. Goodnough, *supra* n. 60, at A1.

85. Abby Goodnough, *Gov. Bush Seeks Another Inquiry in Schiavo Case*, N.Y. Times A1 (June 18, 2005). Focusing on a possible inconsistency between the time Michael remembered calling 911 and the time the call was actually placed, Governor Bush said, "It's a significant question that during this entire ordeal was never brought up." *Id.* Michael responded immediately saying the Governor's actions were "sickening" and said he had called 911 promptly. *Id.*

86. Bob Herbert, *Cruel and Unusual*, N.Y. Times A19 (June 23, 2005). Bernie McCabe, the State Attorney for Pinellas County whom Governor Bush asked to start an investigation, told Herbert he had no indication that a crime had been committed and was conducting what he called an inquiry, rather than an investigation, only because the Governor had requested it: "My purpose . . . is simply to respond to the [G]overnor. The [G]overnor asked me to do something, and I'm going to try to do it." *Id.* On July 8, Bernie McCabe released an investigative report memo to him from two of his investigators, Doug Crow and Bob Lewis, who strongly recommended that the "inquiry be closed and no further action taken" because, among other things, "it is obvious to us that there is no possibility of proving that anyone's criminal act was responsible for Mrs. Schiavo's collapse." Memo. from Doug Crow and Bob Lewis, Prosecutors, St. of Fla., to Bernie McCabe, St. Atty., St. of Fla. 2, 6 (June 27, 2005) (copy on file with the *Stetson Law Review*). McCabe closed the investigation, and Governor Bush discontinued his efforts to further review the case. *Id.*

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refused to accept the facts.⁸⁷ In a June 19 statement released by the Christian Communication Network, he wrote the following:

Dr. Maxfield [a radiologist who was the other expert witness for the parents] and [I] both emphasized that she was a woman trapped in her body, similar to a child with cerebral palsy, and that was borne out by the autopsy, showing greater injury in the motor and visual centers of the brain. *Obviously, the pathologists' comments that she could not see were not borne out by reality, and thus his assessment must represent sampling error. . . . That she could not swallow was obviously not borne out by the reality that she was swallowing her saliva. . . .* Thus there appears to be some limitations to the clinical accuracy of an autopsy in evaluating function. . . . Ultimately, *based on the clinical evidence and the autopsy results, an aware woman was killed.*⁸⁸

President Bush also was unmoved by the facts. His spokesperson, Scott McClellan, said at a June 15 press briefing,

[The autopsy] doesn't change the position that the President took. The President took the position he did for a reason. The President believes we should stand on the side of defending and protecting life. That's why he stood with those who supported efforts to defend her life. This is a sad case. Our thoughts and prayers continue to be with her family and friends.⁸⁹

Senator Frist, on the other hand, has been desperately trying, so far without much success, to distance himself from his original comments made as a physician-Senator, saying, "I never made the diagnosis. . . . I wouldn't even attempt to make a diagnosis

87. Christian Commun. Network, *Statement of William M. Hammesfahr*, <http://www.earnedmedia.org/tf0619.htm> (accessed Aug. 21, 2005).

88. *Id.* (emphasis added). A declaration of Dr. Hammesfahr was also read into the Congressional Record during the debate on the Schiavo bill. In the declaration he declared under oath, "As a patient, Terri Schiavo is not in that bad of a condition to begin with. We treat many patients who are a lot worse. There are a lot of therapies out there that will very likely improve her condition, and they all compliment each other, so if you do them all in a series, she could get a lot better. . . . Without a doubt, I observed Terri swallow. . . ." 151 Cong. Rec. H1712.

89. U.S. Govt., *White House, Scott McClellan Press Briefing*, <http://www.whitehouse.gov/news/releases/2005/06/20050615-3.html> (accessed Aug. 22, 2005).

based on a videotape.”⁹⁰ However, Frist’s comments questioning the diagnosis were caught on C-SPAN, and, among others, Jon Stewart replayed them on *The Daily Show*.⁹¹ Stewart observed, “Not only do I believe that Senator Bill Frist may be a terrible doctor, I think he doesn’t realize C-SPAN has cameras.”⁹² Republican political strategist Tony Fabrizio noted, “It is never good when you say you didn’t do something when you are on camera doing it . . . Frist’s adversaries . . . will use it time and time again.”⁹³ Columnist David Brooks, who is very sympathetic to Frist, nonetheless accurately and succinctly summed it up: “It’s not quite fair to say that Frist diagnosed Schiavo from a TV screen, but he did put himself on the wrong side of the autopsy. . . . He did betray his medical training, which is the core of his being, to please a key constituency group.”⁹⁴ Political cartoonist Mike Luckovich was less kind, picturing Frist at the new King Tut exhibit, saying of Tut, “This young man’s the picture of health.”⁹⁵

The autopsy report, of course, also vindicated the primary expert medical witness for Michael Schiavo, neurologist Ronald Cranford, perhaps the country’s leading expert on vegetative states, and certainly the country’s most experienced examining physician in courtroom controversies revolving around this diagnosis. Over the years of his involvement in this case, Cranford lost all respect for the opinions of Drs. Maxfield and Hammesfahr, whom he sees as quacks. As he has put it,

The following is a sample of the completely fallacious opinions rendered about Terri’s medical condition by Drs. Max-

90. Janet Hook, *Frist Plagued Again by Comments on Schiavo*, L.A. Times A20 (June 17, 2005).

91. *The Daily Show with Jon Stewart* (Comedy Central June 17, 2005) (TV broadcast).

92. *Id.*

93. Hook, *supra* n. 90, at A20.

94. David Brooks, *What Makes Bill Frist Run?* N.Y. Times WK12 (June 19, 2005). Frist would like to forget the whole incident, telling the *Wall Street Journal*, “Knowing what I know now I would have done things differently, but at the time, I think I probably made the right decisions. . . . I think it’s left a negative aura everywhere.” David Rogers, *Still an Enigma, Bill Frist Reflects a Complex Past*, Wall St. J. A1, A10 (June 27, 2005). As the *Editor in Chief of Science*, Donald Kennedy, put it, “The Senate’s chief surgeon, Dr. Bill Frist (R-TN) established a record for definitive long-range TV diagnosis on . . . [persistent vegetative state].” Donald Kennedy, *Silly Season on the Hill*, 309 Sci. 1301 (2005).

95. Mike Luckovich, *Cartoon*, <http://www.ajc.com/opinion/content/opinion/luckovich/2005/061705.html> (June 17, 2005).

field and Hammesfahr. Twelve years after an hypoxic-ischemic insult, and serial CT scans showing extremely severe atrophy of the cerebral hemispheres, both doctors said there was a “chance for recovery,” with the potential for response to treatment. Dr. Maxfield, the radiologist, testified that “abnormal brain dissolves, so what’s left [as seen in the CT scans] is normal, functioning brain.” He further stated that the most recent CT scan shows “improvement.” They gave no published data to support their opinions on their proposed treatments of HBO [hyperbaric oxygen] and vasodilator therapies . . . as effective treatment for patients with chronic brain damage. The articles on the internet on vasodilator therapy, including those by Dr. Hammesfahr, are extremely poorly written, and only a cursory examination of these articles would tell any medical professional that they could not have possibly been peer-reviewed.⁹⁶

After the feeding tube had been removed and Congress had tried to intervene, another neurologist-“bioethicist,” William Cheshire, saw Schiavo and told Governor Bush,

Although Terri did not demonstrate during our [ninety]-minute visit compelling evidence of verbalization, conscious awareness, or volitional behavior, [there is] a distinct presence of a living human being who seems at some level to be aware of some things around her.⁹⁷

Asked to comment on this new finding, Cranford gave the opinion of his fellow neurologist all the respect he believed it deserved, simply saying, “I have no idea who this Dr. Cheshire is. He has to be bogus, a pro-life fanatic.”⁹⁸

VI. BIOETHICS AFTER SCHIAVO

The fact that Cheshire, of whom no one in mainstream American bioethics had ever heard, could simply call himself a bioethicist and be accepted by many in the media as one revealed

96. Ronald Cranford, *Facts, Lies and Videotapes: The Permanent Vegetative State and the Sad Case of Terri Schiavo*, 33 J.L. Med. & Ethics 363, 366–367 (2005). Some nonphysician observers were, however, impressed with Cheshire. *E.g.* Joan Didion, *The Case of Theresa Schiavo*, 52 N.Y. Rev. 10 (June 9, 2005).

97. *Quotes of Note*, Boston Globe A11 (Mar. 26, 2005).

98. *Id.*

something about the politicization of bioethics itself. Whether one dates it from the early 1970s as most do, or from the Nuremberg Doctors' Trial, as I do, American bioethics has welcomed religious thinkers into its ranks but has remained secular and pragmatic.⁹⁹ Under President Bush, however, government-sponsored bioethics turned overtly political when Bush appointed his President's Council on Bioethics with the primary mission of justifying his ban on federal funding of human embryonic stem cell research, and choosing the neoconservative thinker Leon Kass to chair the Council.¹⁰⁰ The Council quickly developed an embryo-centric, anti-abortion, and anti-regulation agenda, which the council has repeatedly failed to transcend.¹⁰¹ This narrow agenda helps explain why, even though the President was personally involved in the *Schiavo* case, and even though the case was at heart a bioethics dispute that involved issues that have been at the core of the work of national bioethics panels for more than two decades, the President never sought the advice of even his own highly political bioethics council on this primarily political matter.

But there is more to it than this. American bioethicists have largely stayed away from the politics of abortion, and when they have engaged in it, they have found that the compromise and pragmatism that have characterized the field were totally unacceptable to the right-to-life organizations—who have now taken to calling some of their own spokespersons “bioethicists.” It was probably inevitable that bioethics and bioethicists would get more involved in politics. But must bioethics accept rigid fundamentalist believers as bioethicists just because they call themselves bioethicists? The fact that religious views are relevant to bioethics should not mean that bioethics can be equated with religious beliefs. The question of whether it is good or bad for bioethics to be embroiled in American politics is no longer relevant; the only

99. George J. Annas, *American Bioethics: Crossing Human Rights and Health Law Boundaries* (Oxford U. Press 2005).

100. The Pres.'s Council on Bioethics, *Leon R. Kass, M.D., Ph.D.*, <http://www.bioethics.gov/about/kass.html> (accessed Aug. 22, 2005).

101. George J. Annas & Sherman Elias, *Politics, Morals and Embryos: Can Bioethics in the United States Rise above Politics?* 431 *Nat.* 19 (2004); see also Arthur Caplan, “Who Lost China?” *A Foreshadowing of Today's Ideological Disputes in Bioethics*, 35 *Hastings Ctr. Rpt.* 12 (May/June 2005) (taking a critical look at the history of U.S. bioethics); Jonathan Moreno, *The End of the Great Bioethics Compromise*, 31 *Hastings Ctr. Rpt.* 14 (Jan./Feb. 2005) (describing politics' role in polarizing the bioethics community).

question is whether bioethicists can retain credibility in a political world much more interested in opinion and controversy than in facts and principles. In the aftermath of the *Schiavo* case, it remains an open question whether bioethicists will have more impact on how Americans think about bioethical issues than political cartoonists or late-night comedians, both of which have been much more successful than the mainstream media at exposing hypocrisy and partisan agendas.

The main reason the *Schiavo* case did not turn out to be a watershed event on the bioethics/religion front can be attributed primarily to the influence of America's two best known bioethicists—Leon Kass and Art Caplan. As the President's bioethicist, Kass would have been expected to play a prominent role, and I believe he did. His public silence was loud and can be explained by the fact that Kass has consistently and eloquently attacked vitalism and has argued against prolonging life at all costs and against seeing immortality as a reasonable medical goal. After *Quinlan*, but before *Cruzan*, he wrote, "even people in the so-called persistent vegetative state must have healthy vegetative functions. . . . But few of us would accept the preservation of such a reduced level of function as a proper *goal* for medicine."¹⁰² Although Kass might or might not support discontinuation of fluids and nutrition in a particular case, he does not accept death as always evil or the continuation of life by medical means as always good. In his words, "I think one can walk between the extremes of vitalism and 'quality control,' and uphold in so doing the respect that life itself commands for itself."¹⁰³ And although he has become a political animal, he could not be comfortable with sloganeering in the *Schiavo* case, having written perceptively that questions of life prolongation

102. Leon Kass, *Toward a More Natural Science* 203 (Free Press 1985) (also quoted by Justice Stevens, dissenting, in *Cruzan*, 497 U.S. at 346) (emphasis in original). The most authoritative bioethics discussion of the issues was by a previous bioethics commission. Pres.'s Commn. for the Study of Ethical Problems in Med. & Biomed. & Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (U.S. Govt. Printing Off. 1983).

103. Kass, *supra* n. 102, at 206. Norman Cantor has persuasively argued that we need to take the human dignity of severely impaired patients much more seriously, and that as a part of this, every profoundly disabled person should have a clearly established right "to have a conscientious surrogate make critical medical decisions according to the best interests of the disabled patient." Norman Cantor, *The Relation between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 *Annals Health L.* 37, 80 (2004).

will not yield to simple formulae such as “death with dignity” or “life is sacred” or “dispense with extraordinary means.” Such terms as “incurable,” “dying,” “terminal,” and “hopeless” are notoriously vague, not to speak of “dignity”. . . . Measures that can be said to be life-preserving span a continuum from respirators and dialysis machines, through antibiotics and insulin, to intravenous glucose and water, even to food and drink.¹⁰⁴

Kass’s silence on *Schiavo* is reassuring; politics has not totally hijacked bioethics, even in the intensely political Bush administration. But bioethicists also have an obligation to speak up when power politics and religious fundamentalists threaten to reverse the good that bioethics has done. And many bioethicists did. Of them, the most consistently articulate was the bioethicist who has become bioethics’s public face in America, Arthur Caplan.¹⁰⁵ Caplan came out early and strongly against congressional intervention, writing a powerful editorial for MSNBC titled “The Time Has Come to Let Terri Schiavo Die” on March 18, 2005, arguing that both bioethics and law supported Michael Schiavo as the decision-maker and that should be the end of it.¹⁰⁶ He also noted, both in the piece and later in other venues, including many CNN and network appearances, that having the right to refuse any medical treatments also served to protect religious practices, at least those of adults, including Christian Scientists

104. Kass, *supra* n. 102, at 204. The Council was working on its own report on end-of-life care during the *Schiavo* litigation, and it was finally published in September 2005. Pres.’s Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society* (Sept. 2005) (available at <http://www.bioethics.gov/reports/taking-care/taking-care.pdf>). The Council continued to go out of its way to ignore *Schiavo*, referencing the case only once, and then just in relationship to living wills.

More recently, the *Schiavo* case has led to renewed calls for living wills: If only she had made her treatment preferences clear in advance, some argued, everyone might have been spared the wrenching decisions, bitter court battles, and national drama that ensued. Of course, the *Schiavo* case—involving sudden injury to a young person, leading to a persistent vegetative state—is hardly paradigmatic of the social and ethical challenge facing our society.

Id. at 54.

105. See U. of Pa., *Center for Bioethics*, <http://www.bioethics.upenn.edu/people/?last=Caplan&first=Arthur> (last updated Jan. 2003) (listing Mr. Caplan’s honors, publications, and professional titles).

106. Arthur Caplan, *The Time Has Come to Let Terri Schiavo Die*, <http://msnbc.msn.com/id/7231440/print/1/displaymode/tz1098/> (last updated Mar. 18, 2005).

and Jehovah's Witnesses.¹⁰⁷ And in calling for more people to sign a living will and designate a healthcare proxy, he joined a veritable chorus of bioethicists urging Americans to take actions that might help avoid getting them and their families in similar circumstances.¹⁰⁸ Caplan did not "save" bioethics in the Schiavo controversy, but he should get credit (and thanks) for postponing a decisive, but seemingly inevitable, confrontation with the religious, anti-abortion community.

VII. HEROES AND VILLAINS, WINNERS AND LOSERS

The final chapter in the case of Terri Schiavo has yet to be written. But it is not too soon to identify some of the heroes and the villains. In my mind, the major heroes are Judges George Greer and James D. Whittemore, both of whom resisted intense political pressure to render opinions based on the law and the facts in the highest tradition of American law. The primary villains are Senator Bill Frist and Representative Tom DeLay, both of whom attempted to use the plight of Terri Schiavo and her family for their personal political gain. Jeb and George Bush were, I think, more pawns than players in this saga. Neither ever claimed to be anything but fundamentalist Christian politicians; therefore, the fact that they succumbed to intense pressure from the religious right came as no surprise.

In terms of winners and losers, conclusions must be tentative, and like the medical examiner's report, subject to revision upon receipt of additional credible information. Nonetheless, it seems fair to conclude that the big loser in the Schiavo debate was Congress, and the big winner was the rule of law and our court system. This is because the primary message of the radical religious right turned out to be widely mistaken—both in its medical diag-

107. *Id.*; see also Nancy Grace, "Terri Schiavo Dies" (CNN Mar. 31, 2005) (TV broadcast, transcr. available at LEXIS, ALLNEWS file) (remarking that the Jehovah's Witnesses' and Christian Scientists' right to decline medical treatment allows them to control how they die).

108. Caplan was well positioned to be the unofficial spokesperson for the bioethics community not only because he has the ability to engage in sound-bite debate better than any other bioethicist in the United States, but also because his own career as a public bioethicist began when the Hastings Center started getting press inquiries about the case of Karen Ann Quinlan in 1976; because most of the bioethics staff there was away at a conference, he wound up taking the calls and has not looked back.

nosis of Terri Schiavo, and more importantly, in its diagnosis of the wishes of the American people. Overwhelming majorities of Americans in every major poll taken after Congress passed the Theresa Schiavo Act found that Americans do not want Congress involved in life-and-death medical decisions, but believe these should be made by families who know the individuals involved and can best articulate their wishes.¹⁰⁹ Moreover, the public agreed with the determination of the courts in the *Schiavo* case itself.¹¹⁰ In short, as Professor Jeffrey Rosen has astutely observed in a broader context, including not only *Schiavo*, but also the filibuster debate and even *Roe v. Wade*,

[T]he conservative interest groups have it exactly backward. Their standard charge is that unelected judges are thwarting the will of the people by overturning laws passed by elected representatives. But in our new topsy-turvy world, it's the elected representatives who are thwarting the will of the people, which is being channeled instead by unelected judges.¹¹¹

The *Schiavo* case may have changed politics and bioethics by making the public more cynical about both; but it has not changed the law. It is probably too much to hope that the case will help demonstrate the shallowness and vapidness of the slogan “err on

109. For example, an April 1–2 CNN/USA Today poll found seventy-six percent of Americans disapproved of congressional involvement in the *Schiavo* case, and only twenty percent approved. Susan Page, *Many Wary of GOP's Moral Agenda*, USA Today 1A (Apr. 6, 2005). An earlier, March 21–22 poll by CBS News found eighty-two percent of Americans saying Congress and the President should stay out of deciding what happens to Terri Schiavo, and only thirteen percent thinking they should be involved. *CBS News Poll 2* (CBS News Mar. 23, 2005). Likewise, a *Time* poll taken March 22–24 found seventy-five percent of Americans saying it was “not right” for Congress to intervene in the *Schiavo* case, and twenty percent thinking it was right. *People's Memo to Politicians: This Is Not Your Fight*, Time Mag. 26 (Apr. 4, 2005) [hereinafter *People's Memo*].

110. An ABC News poll taken March 20 showed that the public, by a sixty-three percent to twenty-eight percent margin supported the removal of the feeding tube. Gary Langer, *Poll: No Role for Government in Schiavo Case*, <http://abcnews.go.com/politics/print?id=599622> (Mar. 21, 2005). Similar, but closer, margins were found on other polls. Page, *supra* n. 109, at 1A; *People's Memo*, *supra* n. 109, at 26; *CBS News Poll*, *supra* n. 109, at 2. The *Time* poll of March 22–24 found fifty-nine percent agreed with the decision to remove the feeding tube, and thirty-five percent disagreed. *People's Memo*, *supra* n. 109, at 26. The CNN/USA poll of April 1–2 found the margin closer, fifty-two percent agreeing with the decision to remove the tube and forty-two percent opposing. Page, *supra* n. 109, at 1A.

111. Jeffrey Rosen, *Center Court*, N.Y. Times WK 6–17 (June 12, 2005).

the side of life” in this context, which has about as much depth as slogans like “look before you leap” and “he who hesitates is lost.” Life-or-death decisions are easy. But when a person’s brain is irreversibly destroyed, life has no side—it is only a question of how the dying process will proceed. To deny this is to not only to deny the medical facts, it is to revert to mindless vitalism—a concept no religion that believes in an afterlife can support. We all “want to live”; but most Americans recognize that, ultimately, we will all die, and that dying in America remains more fearsome than death—and immortality is not an option.¹¹²

Terri Schiavo was abused by the political system and used as a voiceless vessel for anyone with a cause who claimed to speak for the cause on her behalf. Although she and her husband ultimately prevailed in court, it was a bitter legal victory. No one should have his or her private life subjected to such intense and vicious public scrutiny for trying to do what his or her spouse would have wanted. There is no escaping the fact that when we are unable to make medical decisions for ourselves, someone else will have to make them for us. It will be easier on all our friends and family if we each designate a decision-maker ourselves. Decisionmaking at the end of life will never be easy and should never be formulaic; furthermore, families that were dysfunctional when one member was healthy are not usually healed when the member becomes incapacitated. But we should nonetheless maintain the presumption that close family members are the best decision-makers and insist that end-of-life decisionmaking stay within the family, and out of the hands of politicians. Courts must remain available, but used only in cases, like the case of Terri Schiavo, where conflicts are not reconcilable.

Terri’s tombstone accurately summarizes her life and her husband’s efforts to fulfill her wishes: “SCHIAVO, THERESA MARIE, BELOVED WIFE, BORN DECEMBER 3, 1963, DEPARTED THIS EARTH FEBRUARY 26, 1990, AT PEACE

112. For more on slogans in this context see George J. Annas, *The “Right to Die” in America: Sloganeering from Quinlan and Cruzan to Quill and Kevorkian*, 34 Duq. L. Rev. 875 (1996). It is also worth noting that the more typical response to the mindless continuation of medical treatment at the end of life is to advocate for physician-assisted suicide rather than decent palliative care which, if universally available, would drastically reduce suicide’s appeal.

MARCH 31, 2005, I KEPT MY PROMISE.”¹¹³ Terri Schiavo is now beyond further abuse by the political system; but fundamentalist religious fanatics remain capable of inflicting further harm on society, and only an informed citizenry that insists on keeping highly personal decisions out of the hands of government, insists on separation of church and state, and insists that the courts, not Congress, interpret the United States Constitution can save us all from a “salvation” we neither seek nor can live with on this earth.

113. David Sommer, *Husband Changes Course, Buries Schiavo Locally*, Tampa Trib. Metro 1 (June 1, 2005).