IN THE SUPREME COURT OF THE STATE OF FLORIDA

JEB BUSH,

Governor of the State of Florida,

Appellant,

CASE NO.: SC04-925

v.

MICHAEL SCHIAVO, as Guardian of the Person of THERESA MARIE SCHIAVO,

Appellee.

BRIEF OF *AMICI CURIAE* NOT DEAD YET *ET AL.* IN SUPPORT OF APPELLANT AND REQUESTING REVERSAL

(Full listing of Amici on inside cover)

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CENTER ON SELF DETERMINATION

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NATIONAL DISABLED STUDENTS UNION

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SELF-ADVOCATES BECOMING EMPOWERED

SOCIETY FOR DISABILITY STUDIES

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WORLD ASSOCIATION OF PERSONS WITH DISABILITIES

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INTRODUCTION AND STATEMENT OF INTEREST

Amici are among the nation's leading civil rights organizations representing people with disabilities.[1] Many are staffed and governed by a majority of people with disabilities of all types, including severe physical and cognitive disabilities, and their families. They led the movement to enact the Americans with Disabilities Act, 42 U.S.C. § 12101, and other civil rights laws protecting persons with disabilities. They join here to support HB 35-E because the standards upon which Ms. Schiavo's life or death turn may, if defined broadly enough, also be applied to thousands of people with disabilities who, like Ms. Schiavo, cannot readily articulate their own views and must rely on third parties as substitute decision-makers. The need for limits on the powers of such decision makers is nowhere more clear that on a question as fundamental as life or death, because the consequences of abuse or misjudgment are both ultimate and irreversible. For this reason, neither a court nor any third party may base a decision on their own view of the affected person's "quality of life." Only the person's own desires may drive this determination.

The reasons behind the disability community's solidarity with Ms. Schiavo may not be immediately apparent. Yet a close examination of the issues shows that Ms. Schiavo's fate is intertwined with that of many people with disabilities

[1] Organizations and individuals joining as *amici* are listed on the inside of the cover.

who must rely on surrogates. If the legal standard of proof in cases involving termination of life support is watered down to the point where Ms. Schiavo's "quality of life" – as determined by others – justifies her death, then one cannot distinguish Ms. Schiavo from anyone else who is "incompetent," including thousands who cannot speak due to developmental or physical disabilities. It is naïve to believe such attitudes would not be used to justify the death of people with severe disabilities if the opportunity arose. For example, prominent ethicists such as Peter Singer of Princeton University have sanctioned the killing of people with severe disabilities based on a belief that they will not lead a "good" life and will burden their parents and society.[2]

These attitudes, which have a long and ugly history as justification for the sterilization or elimination of people with disabilities,[3] may be nothing more than privately held prejudices. Yet they don the cloak of public sanction every time a court lowers the constitutional bar on substituted judgments and consequently

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[2] Professor Singer has written that it is impossible to kill people with cognitive disabilities "against their will" "because they are not capable of having a will on such a matter." P. Singer, *Rethinking Life and Death: The Collapse of Our Traditional Ethics* 197-98 (1994). *See also* Harriett McBryde Johnson, "Unspeakable Conversations: The Case for My Life," *N.Y. Times Magazine*, Feb. 16, 2003.

[3] *See e.g. Buck v. Bell*, 274 U.S. 200, 207 (1927) (in upholding sterilization of woman with mental retardation, Court held that "[i]t is better for all the world, if instead of waiting to execute degenerate offspring of crime, or to let them starve from their imbecility, society can prevent those who are manifestly unfit from continuing their kind … Three generations of imbeciles is enough.").

broadens the category of people with disabilities whose lives may be terminated. For these reasons, *Amici* urge reversal of the trial court below.

SUMMARY OF ARGUMENT

HB 35-E is valid prospective legislation designed to protect the rights of certain persons with disabilities who have not stated, and are currently unable to state, their desires. It exemplifies the principle that the legislature may, by amending the law, effectively reverse a judicial decision. Congress has repeatedly done so to protect the civil rights of people with disabilities, women and minorities. HB 35-E does not dictate to Florida courts how a case should be decided, does not require final judgments to be reopened and does not grant the Governor the ability to "review" court decisions. As applied to Ms. Schiavo, HB 35-E reverses only the consequence of a judgment for an incapacitated woman who may not want to die.

The lower court also found that HB 35-E infringed on Ms. Schiavo's right to privacy, specifically her right to refuse medical treatment. This finding ignores Ms. Schiavo's equally-fundamental right not to have medical treatment – particularly life-sustaining treatment – withdrawn by a third party absent clear and convincing evidence that Ms. Schiavo would have made that decision herself. HB 35-E acts to preserve this right for Ms. Schiavo, whose actual desires are unclear and heavily disputed. Because the consequences of an erroneous decision to

withdraw treatment are permanent and fatal, this Court should find that HB 35-E does not infringe on and is in fact entirely consistent with Ms. Schiavo's due process rights.

ARGUMENT

I. HB 35-E IS VALID, PROSPECTIVE LEGISLATION THAT DOES NOT VIOLATE THE SEPARATION OF POWERS DOCTRINE

A. The legislature may enact prospective legislation that affects a judicial decision

Although both the Florida and the United States Constitutions mandate separation of powers, the three branches of government do not exist in a vacuum. Courts have recognized the legislature has the "last word" on statutory interpretation. *Henderson v. Scientific-Atlanta*, 971 F.2d 1567, 1571-72 (11th Cir. 1992) ("If Congress disagrees with the Supreme Court's interpretation, it is free to amend the statute as it sees fit. *Indeed, this is how our federal system is designed to operate.*") (emphasis added). "Generally speaking, legislation is presumed to be valid." *Jackson v. State Bd. of Pardons & Paroles*, 331 F.3d 790, 797 (11th Cir. 2003).

To overcome this presumption on separation of powers grounds, courts must find that a law 1) "prescribe[s] rules of decision to the Judicial Department of the government in cases pending before it," *Plaut v. Spendthrift Farm, Inc.*, 514 U.S. 211, 218 (1995) (quoting *United States v. Klein*, 80 U.S. 128, 146 (1872)); 2) vests

review of court decisions in the Executive branch, *id.*; or 3) retroactively commands a federal court to reopen a final judgment. *Id.* at 219. The separation of powers doctrine is thus a narrow exception to the legislature's authority to enact laws.

HB 35-E falls under none of these categories. It does not tell Florida courts how to decide a case, nor require them to reach a particular decision. HB 35-E does not reopen a judgment or grant the Governor the power to "review" court decisions. Rather, it is prospective legislation that granted the Governor the power to re-insert a feeding tube under certain (albeit limited) circumstances. While this undoubtedly affected the case between Ms. Schiavo's parents and husband — and was intended to do so — it is distinct from what courts have long understood to be among the activities that infringe on the judiciary. Were it not for the background behind HB 35-E, the Act would not be questioned because it represents an eminently reasonable legislative act.

It is well settled that subsequent legislation may affect and even reverse the effects of judgments without violating separation of powers. Indeed, "Congress has often introduced retroactive legislation in reaction to specific judicial decisions without creating a separation of powers problem." *O'Brien v. J. I. Kislak Mortgage Corp.*, 934 F. Supp. 1348, 1361 (S.D. Fla. 1996) (citing *Rivers v. Roadway Express*, 511 U.S. 298, 305 n.5 (1994) ("according to one commentator,

between 1967 and 1990, the legislature overrode 'our decisions at an average of ten per Congress.'") (citation omitted). In *Henderson*, the Eleventh Circuit upheld a statute that effectively reversed a judgment because the law did not "require courts to make any particular findings of fact or applications of law to fact." 971 F.2d at 1573. Similarly, HB 35-E does not require Florida courts to make any specific findings of fact or order the judiciary to decide a case a particular way.

Even though the law in question was intended to apply specifically to Ms. Schiavo, this does not in and of itself render the statute unconstitutional. In *Robertson v. Seattle Audubon Soc'y*, 503 U.S. 429 (1992), the Supreme Court unanimously rejected a separation of powers challenge to a statute intended solely to resolve particular litigation. In *Robertson*, environmental groups had filed suit over logging rights in thirteen national forests. In response, Congress enacted the Northwest Timber Compromise, a law expressly designed to settle these lawsuits and nothing more:

> The Congress hereby determines and directs that management of areas…is adequate consideration for the purpose of meeting the statutory requirements that are the basis for the consolidated cases captioned Seattle Audubon Society, et al., v. F. Dale Robertson…and Washington Contract Loggers Assoc. et al., v. F. Dale Robertson.

Id. at 434-35 (quoting 101 P.L. 121 § 318(b)(6)(A)). The *Robertson* Court held that although the statute was "in response to this ongoing litigation," *id.* at 433, it

was nonetheless constitutional because it "compelled changes in law, not findings or results under old law." *Id.* at 438.

Like HB 35-E, the Northwest Timber Compromise was limited in scope and duration. It applied only to the "thirteen national forests in Oregon and Washington" that were the subject of the environmental lawsuits. *Id.* at 433. It also contained an automatic expiration date. *Id.* Neither rendered the statute an unconstitutional infringement on the judiciary. *Id.* at 441. Likewise, HB 35-E's temporal and specific limitations do not cause it to be unconstitutional.[4]

B. HB 35-E does not give the Governor the power to reopen final court judgments

In contrast to the facts in *Plaut*, 514 U.S. at 227 — in which a law opened old judgments retroactively by modifying a statute of limitations — HB 35-E does not mandate that a case be reopened and retried. HB 35-E sets prospective standards that affect only the *consequence* of a judgment—in this case, the death of an incapacitated woman who may not have wanted to die. Courts have repeatedly found that this sort of legislative action is entirely permissible. While HB 35-E grants Mrs. Schiavo relief, it does not reflect the "oppressive action that the

[4] The Florida Supreme Court has recognized that the separation of powers provisions in the Florida and United States Constitutions are "parallel." *In re Apportionment Law Appearing as Senate Joint Resolution 1E, 1982 Special Apportionment Session; Constitutionality Vel Non*, 414 So. 2d 1040, 1061 (Fla. 1982) (citing *McPherson v. Flynn*, 397 So. 2d 665, 667 (Fla. 1981)).

separation of powers was designed to avoid." *Plaut,* 514 U.S. at 242 (Breyer, J., concurring).

C. Congress has repeatedly acted in the realm of civil rights to overturn judicial decisions that infringe on those rights

On numerous occasions, Congress has enacted prospective legislation to reverse the effects of court decisions that, contrary to the law's intent, curtailed civil rights. Such legislation has been a critical tool for civil rights advocates in preserving fundamental civil rights of persons with disabilities, women and racial minorities.

For example, the Civil Rights Act of 1991 reversed what Congress saw as an erroneous judicial decision curtailing the ability of civil rights victims to enforce their rights. In *Wards Cove Packing Co. v. Antonio*, the Supreme Court heightened the standard for showing that an employer's hiring practices had a significant disparate impact on non-white employees. 490 U.S. 642 (1989). Congress found that "…the decision of the Supreme Court in *Wards Cove Packing Co. v. Antonio* … has weakened the scope and effectiveness of Federal civil rights protections." 102 P.L. 166, 105 Stat. 1071 (1991) (amending Title VII of the 1964 Civil Rights Act, 42 U.S.C. § 2000e). Thus, although the Act undeniably overrode a Supreme Court decision and restored the viability of previously dismissed cases, it was well within the legislature's right to amend a statute if it found the Court's interpretation to be contrary to legislative intent.

In *Grove City Coll. v. Bell*, 465 U.S. 555, 574 (1984), and *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624, 635-36 (1984), the Court held that Title IX and Section 504 of the Rehabilitation Act of 1973,[5] respectively, covered only the portions of programs that directly received federal funds, excluding any part of programs that did not receive those funds. These decisions significantly narrowed civil rights protections for people with disabilities, women and minorities. Congress responded with the Civil Rights Restoration Act "to overturn the Supreme Court's decision in *Grove City College v. Bell* … and to restore the effectiveness and vitality of the four major civil rights statutes … that prohibit discrimination in federally assisted programs." S. Rep. No. 100-64 (Jun. 5, 1987) at 2, *reprinted in* 1988 U.S.C.C.A.N. 3, 4. The Act made it possible for civil rights plaintiffs whose cases had been dismissed under *Grove City* and *Darrone* to have their claims reinstated.

In *Atascadero State Hosp. v. Scanlon*, 473 U.S. 234 (1985), the Court held that Congress had not clearly stated its intent to condition federal funding upon the states' waiving their Eleventh Amendment immunity, and as a result found that states were immune from lawsuits under Section 504. *Id.* at 240. Congress

[5] Section 504 of the Rehabilitation Act is the predecessor to the Americans with Disabilities Act. Although Section 504 covers only federally-assisted programs, its substantive protections are the same as those under the ADA. *Helen L. v. DiDario*, 46 F.3d 325, 330 n. 7 (3d Cir.), *cert. denied sub nom., Pennsylvania Sec'y of Publ. Welf. v. Idell S.*, 516 U.S. 813 (1995).

responded with the Rehabilitation Act Amendments of 1986, which stated that as a condition of federal assistance, states are subject to lawsuit for civil rights violations—a direct reversal of *Atascadero State Hospital.* 99 P. L. 506, 100 Stat. 1807 (amending 42 U.S.C. § 2000d-7 (1986)). This law reinstated claims that had been judicially barred, again without unconstitutionally infringing upon the power of the courts.

Finally, in *Smith v. Robinson*, 468 U.S. 992 (1984), the Court held that the Education of the Handicapped Act (now the Individuals with Disabilities Education Act) did not provide for awards of attorney's fees. In response, Congress enacted the Handicapped Children's Protection Act, 99 P. L. 372, 100 Stat. 796 (1986), "to amend the Education of the Handicapped Act to authorize the award of reasonable attorney's fees to certain prevailing parties, to clarify the effect of the [EHA] on rights, procedures, and remedies under other laws relating to the prohibition of discrimination." *Id* (amending 20 U.S.C. § 1415).

These laws demonstrate that Congress has often acted to overturn what it viewed as judicial decisions that erroneously curtailed the scope of and remedies under civil rights laws. As a result, civil rights plaintiffs whose cases had been dismissed were able to reopen those cases if their claims met other requirements for adjudication. These cases illustrate the vital principle that the legislature must

be able to act to remedy erroneous judicial interpretations of civil rights statutes. HB 35-E is consistent with this principle.

II. THE LEGISLATURE ACTED TO PROTECT MS. SCHIAVO'S CONSTITUTIONAL RIGHT TO PREVENT HAVING HER LIFE TERMINATED BY A THIRD PARTY

A. Ms. Schiavo's right to refuse treatment is countered by her right to avoid withdrawal of life-sustaining treatment by a third party against her wishes

The trial court below erroneously ruled that HB 35-E violated Ms. Schiavo's constitutional right to refuse treatment. However, the Court ignored Ms. Schiavo's countervailing and equally fundamental right not to have a third party usurp that decision and terminate her life when that would not have been what Ms. Schiavo wanted. It is this issue that strikes at the heart of the civil rights of people with disabilities. In this regard, HB 35-E must be viewed in the context of ensuring that the decision to withdraw treatment was truly Ms. Schiavo's and no one else's.

The seminal case on the constitutional limits of authorizing a incapacitated person's death is *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261 (1990).[6] There, the United States Supreme Court upheld the Missouri Supreme

[6] The lower court implied that the right to refuse unwanted medical treatment is unique to the Florida Constitution; therefore, decisions under the U.S. Constitution have no bearing on this case. *Schiavo v. Bush*, No. 03-008212-CI-20, slip op. at 6 (Fla. Cir. Ct. Pinellas County May 14, 2004). This is patently incorrect. *Washington v. Harper*, 494 U.S. 210, 221-22 (1990) (state prisoners "possess[] a significant liberty interest in avoiding the unwanted administration of antipsychotic drugs under the Due Process Clause."); *Mills v. Rogers*, 457 U.S.

Court's refusal to authorize withdrawal of life support from Nancy Cruzan, a woman in a persistent vegetative state, because no "clear and convincing evidence" existed that Ms. Cruzan would have asked for withdrawal of life support. *Id*. at 284. The Court recognized Ms. Cruzan (like Ms. Schiavo) held a general right to refuse treatment—including life-sustaining measures—and did not lose this right by virtue of her incapacity. However, the Court focused on Ms. Cruzan's inability to exercise this right, namely by stating whether or not she would have chosen to refuse life-sustaining measures:

> The difficulty with petitioners' claim is that in a sense it begs the question: An incompetent person is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right. Such a "right" must be exercised for her, if at all, by some surrogate.

Id. at 280.

The Court held that it was constitutionally appropriate to demand clear and convincing evidence that the incapacitated person would have chosen to withhold life-sustaining treatment. A court must find that "the patient held a *firm and settled commitment* to the termination of life supports under the circumstances." *Id.* at

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291, 300 n. 16 (1982) ("[W]e assume … that involuntarily committed mental patients do retain liberty interests protected directly by the Constitution … and these interests are implicated by the involuntary administration of antipsychotic drugs."); *Rogers v. Okin*, 478 F. Supp. 1342, 1369 (D. Mass. 1979), *aff'd in relevant part*, 634 F.2d 650 (1st Cir. 1980). Therefore, decisions under the U.S. Constitution are relevant here; moreover, the express privacy rights in the Florida Constitution cannot serve to override Ms. Schiavo's other fundamental rights that are implicated by an erroneous judgment on what her desires would have been.

285 n. 11 (quoting *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 613 (N.Y. 1988)) (emphasis added); *see also In re Guardianship of Browning*, 543 So. 2d 258, 273 (Fla. 2nd DCA 1990) (quoting *Slomowitz v. Walker*, 429 So. 2d 797, 800 (Fla. 4th DCA 1983)). By requiring this level of proof, the Court rejected the objective "best interests" standard, stating that states can decline to "make judgments about the 'quality' of life that a particular individual may enjoy." *Cruzan*, 497 U.S. at 281. Florida has adopted this standard. *Browning*, 543 So. 2d at 269 ("[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*.") (emphasis added) & 273 ("In cases of doubt, we must assume that a patient would choose to defend life in exercising his or her right to privacy.").

This exacting standard is based on the State's competing and compelling interest in preserving human life, *Cruzan*, 497 U.S. at 281, as well as ensuring that the decision to live or die is truly that of the incapacitated person rather than the surrogate. Cases like Ms. Schiavo's raise competing individual interests under the Due Process Clause—the right to refuse treatment *as well as* the right to life. *Id*. ("It cannot be disputed the Due Process Clause protects an interest in life.") *Conservatorship of Wendland*, 28 P.3d 151, 163 (Cal. 2001) ("[T]he right to an appropriate decision by a court-appointed conservator does not necessarily equate with the conservatee's right to refuse treatment, or obviously take precedence over

the conservatee's right to life …"). And while a surrogate could potentially override either interest by acting against the person's wishes, the *Cruzan* Court recognized the greater danger lies in wrongly deciding that the person would want to die:

> An erroneous decision not to terminate results in the maintenance of the status quo; the possibility of subsequent developments such as advancement in medical science, the discovery of new evidence regarding the patient's intent, changes in the law…at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.

Cruzan, 497 U.S. at 283.

The Supreme Court also expressed skepticism about the ability of third parties accurately to prognosticate the wishes of a person who is incompetent. *Id.* at 281. The Court recognized that in "some unfortunate situations … family members will not act to protect a patient." *Id*. (quoting *In re Jobes*, 108 N.J. 394 (1987)). Thus, states "are entitled to guard against potential abuses in such situations." *Id*.

Like *Cruzan*, Florida law also recognizes the need for heightened protections when the "right" to refuse treatment is exercised by a third party. In *Browning*, the Florida Court of Appeals noted:

> When a person is no longer competent to exercise his or her own right of self-determination, the right still exists, but the decision must be delegated to a surrogate decisionmaker. This delegation requires

> *thoughtful guidelines* to assure that the decision fulfills the patient's right of self-determination rather than some other interest.

543 So. 2d at 267 (emphasis added). The Court of Appeals also expressed concern that third party decision-making in this context has the potential for abuse:

> The Ethics and Advocacy Task Force, as amicus curiae, raises a very legitimate concern that the "right to die" could become a license to kill. There are times when some people believe another would be "better off dead" even though the other person is still fighting vigorously to live…the world has witnessed the extermination of retarded and mentally disturbed persons for whom a foreign government decided that death was the proper prescription…the remedy announced in this opinion and the decisions designed to safeguard that remedy are based upon *the patient's right to make a personal and private decision and not upon other interests*.

Id. at 269 (emphasis added). Due to the fundamental life interests at stake, it would undoubtedly be unconstitutional for any state to fail to guard against these potential abuses.

It is therefore not surprising that most states – including Florida – have adopted the objective "clear and convincing" standard of proof upheld in *Cruzan* for cases where a guardian purports to exercise an incapacitated person's right to refuse life-sustaining treatment. *Browning*, 543 So. 2d at 273; *see also McConnell v. Beverly Enterprises-Conn.*, 553 A.2d 596, 604-05 (Conn. 1989); *In the Matter of Tavel*, 661 A.2d 1061, 1070 (Del. 1995); *In re Martin*, 538 N.W. 2d 399, 409-11 (Mich. 1995); *Matter of Conroy*, 321 A.2d 1209, 1218, 1242-43 (N.J. 1985); *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 193 (N.D.N.Y. 2002); *Wendland*, 26 Cal. 4th at 542-43.

Given this standard, it is not surprising the Legislature was troubled by the application of the law in Terri Schiavo's case. The manner in which the law's evidentiary standard was applied to Ms. Schiavo differs sharply from how it was applied in *Browning*. In that case, the affected individual – who was 86 years old – had declared her intent to withdraw treatment via a living will. 543 So. 2d at 262. In Terri Schiavo's case, there was no such living will, no independent advocate, and conflicting testimony from her family and friends over what her true desires would have been. The decision to terminate Ms. Schiavo's life under these circumstances involved a disregard of the "thoughtful guidelines" required by the Court in *Browning* to ensure that her life support was not being terminated against her wishes. As in other areas where the judiciary has contravened the rights of people with disabilities, the Florida Legislature was justified in acting prospectively to ensure Ms. Schiavo's rights were protected.

B. HB 35-E must be seen in the context of the denial of medical treatment based on disability

The withholding of medical treatment based on disability has a long, pervasive and tragic history in the United States. This medical discrimination has taken many forms, including:

- Euthanasia, in which nondisabled persons advocated for the involuntary deaths of approximately 60,000 people in state institutions, and 300,000 outside institutions, because in such "hopeless" cases "we have no fear of

error." F. Kennedy, "The Problem of Social Control of the Congenital Defective," 99 *Am. J. Psych.* 13-16 (1942).[7]

- The "eugenics" movement, in which state laws favored "the killing of defective children." D.B. Shurtlett, "Myelodysplasia: Management and Treatment," 10 *Current Problems in Pediatrics* 1, 8 (1980).[8]
- Involuntary sterilization of persons with developmental and physical disabilities. *Buck v. Bell*, 274 U.S. 200, 207 (1927).[9]
- Denial of life-saving medical assistance, especially to children with severe physical disabilities.[10]

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[7] *See also* "The Right to Kill," *Time*, Nov. 18, 1935, at 53-54 (where a Nobel Prize winner at the Rockefeller Institute urged that "sentimental prejudice... not obstruct the quiet and painless disposition of incurable... and hopeless lunatics"); D. McKim, *Heredity and Human Progress* 189,193 (1900)(where a respected New York physician advocated the elimination of all children with severe disabilities, including "idiots," most "imbeciles, and the greater number of epileptics," for society's protection, via a "gentle, painless death" by the inhalation of carbonic gas).

[8] *See also* Nat Hentoff, "Are Handicapped Infants Worth Saving?" *Village Voice*, Jan 8, 1991, at 18; Richard J. Neuhaus, "The Return of Eugenics," *Commentary* 15-26 (Apr. 1988); Edwin Black, *War Against the Weak* (2003).

[9] *Buck* was decided notwithstanding the Supreme Court's ruling four years earlier that the historical practice of "'putting away … the offspring of the inferior, or of the better when they chance to be deformed,'… [would] do … violence to both the letter and spirit of the Constitution." *Meyer v. Nebraska*, 262 U.S. 390, 401-02 (1923).

[10] Studies have revealed that many physicians, a majority in some specialties, oppose lifesaving surgery for babies with lifelong disabilities. A. Shaw et al., "Ethical Issues in Pediatric Surgery," 60 *Pediatrics* 588, 590 (1977); R.H. Gross et al., "Early Management and Decision-Making for the Treatment of Myelomeningocele," 72 *Pediatrics* 450, 456 (1983) (reporting on the results of

- Withdrawal of medical treatment.

Every state in the Union, including Florida, enacted laws that denied people with disabilities needed medical services and robbed them of their very humanity. In Florida, the unabashed purpose of the first state institution for people with developmental disabilities (called the "Florida Farm Colony for the Epileptic and Feeble-Minded") was so "that these unfortunates may be prevented from reproducing their kind, and the various communities and State at Large relieved

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selection of disabled newborns for treatment between 1977 and 1982 at Oklahoma University Health Sciences Center that babies were provided – or denied – treatment based on such factors as their ambulatory potential, according to a "formula that also factored in the 'contribution anticipated from his home and family and society'"); D. Crane, *The Sanctity of Social Life* 96-98 (1975) (documenting that surgeons at a teaching hospital were *less* likely to perform surgery on Down Syndrome children with heart defects than survey studies would predict).

An early-20th Century front-page story in the *New York Times* highlighted the refusal of a hospital to provide life-saving treatment to a disabled newborn:

> John Bollinger, the baby boy condemned as a hopeless defective *and therefore not operated on*, died early this evening in the German-American Hospital. The child was five days old … Its life, Dr. H.J. Haiselden, the attending physician said, might have been saved by an operation, but this he did not feel justified in performing. The partial paralysis and the malformations, he said, were so great a bar to happiness or attainment that he did not feel justified in saving the baby from the death which nature ordained …

Defective Baby Dies as Decreed: Physician, Refusing Saving Operation, Defends Course as Wisest for Country's Good, New York Times, Nov. 18, 1915, at 1 (emphasis added).

from the heavy economic and moral losses arising by reason of their existence." Ch. 7887 § 8, Laws of Fla. (1919).

The Supreme Court has recognized that the practice of withholding lifesaving medical assistance by medical professionals from children with severe disabilities has a "history of unfair and often grotesque mistreatment" arising from a legacy of "prejudice and ignorance" that continued well into the 20th Century. *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432, 453 (1985) (Stevens, J., joined by Burger, C.J., concurring). Just this Term, the Supreme Court recognized the role of the judiciary in perpetuating the legal regime of discrimination against people with disabilities in medical decisions. *Tennessee v. Lane*, __ U.S. __, 124 S. Ct. 1978, 1995 (2004) (Souter, J., concurring).[11]

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[11] Justice Souter observed:

> Laws compelling sterilization were often accompanied by others indiscriminately requiring institutionalization, and prohibiting certain individuals with disabilities from marrying, from voting, from attending public schools, and even from appearing in public. One administrative action along these lines was judicially sustained in part as a justified precaution against the very sight of a child with cerebral palsy, lest he "produce a depressing and nauseating effect" upon others. *State ex rel. Beattie v. Board of Ed. of Antigo*, 169 Wis. 231, 232, 172 N. W. 153 (1919) (approving his exclusion from public school) … Many of these laws were enacted to implement the quondam science of eugenics, which peaked in the 1920's, yet the statutes and their judicial vindications sat on the books long after eugenics lapsed into discredit.

Id.

This record, perpetrated by force of state law, was based on the premise, advanced by non-disabled people, that people with severe disabilities could not live a "good" life. The law's demanding standard of proof for cases in which a non-disabled third party attempts to deny medical treatment under the guise of asserting the person's constitutional rights – particularly when the consequence is death – is a direct and belated remedy to this historical discrimination. HB 35-E follows this tradition by focusing on the wishes and desires of Terri Schiavo rather than the subjective views of others concerning her "quality of life."

CONCLUSION

For the reasons stated above, *Amici* respectfully request that this Court reverse the lower court's grant of summary judgment.

Dated July 12, 2004. RESPECTFULLY SUBMITTED,

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CERTIFICATE OF COMPLIANCE WITH FLA. R. APP. PROC. 9.210(a)(2)

I certify that the foregoing brief complies with the font requirement of Florida Rule of Appellate Procedure 9.210(a)(2), in that it is written in 14-point Times New Roman font.

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MAX LAPERTOSA