

IN THE SUPREME COURT OF PENNSYLVANIA

No. 98 MAP 2009

IN RE: DAVID L. HOCKENBERRY, an incapacitated person

APPEAL OF MYRL L. and VADA B. HOCKENBERRY

BRIEF OF *AMICI CURIAE* DR. GEORGE ISAJIW, DR. JOHN A.
FLAMINI, DR. JOHN M. TRAVALINE, DR. KARL BENZIO,
and the PENNSYLVANIA FAMILY INSTITUTE

Appeal from the Apr. 14, 2009 denial of the Appellants' application for reargument in the Superior Court of Pennsylvania, Middle District, following the Feb. 10, 2009 Opinion and Order of the Superior Court, No. 336 MDA 2008, which affirmed the Jan. 24, 2008 Opinion and Order of the Cumberland County Court of Common Pleas, Orphans Court Division, No. 21-02-293, denying the Petition of Myrl L. and Vada B. Hockenberry to be appointed as Health Care Agents for David L. Hockenberry

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INTEREST OF AMICI CURIAE

Dr. George Isajiw is Board Certified in internal medicine and has been in the private practice of Internal Medicine in Delaware County, Pennsylvania for 35 years. He has extensive experience in treating severely ill adults and terminally ill patients. He is an active attending staff member at Mercy Fitzgerald Hospital in Darby, Pennsylvania, at Delaware County Memorial Hospital in Drexel Hill, Pennsylvania, and at five area nursing homes.

Dr. John A. Flamini is a Board Certified adult neurologist and has been in private practice since 1983. He has been an active medical staff member at St. Vincent Health Center in Erie, Pennsylvania since that time, where he has served as a chairman of the St. Vincent Health Center Bioethics committee and still serves on that committee. Dr. Flamini has over 25 years of experience diagnosing and treating neurologic diseases. He has significant experience in treating patients of diminished mental capacity such as Mr. Hockenberry, and in counseling patients and families regarding end-of-life issues, ordinary/extraordinary levels of care and proportionate/disproportionate care. Dr. Flamini also sits on the Roman Catholic Diocese of Erie Medical-Moral Advisory Board.

Dr. John M. Travaline is Professor of Medicine at Temple University School of Medicine. He has been a faculty member of Temple University School of Medicine since 1994. He continues to practice actively in the area of pulmonary and critical care, and is board-certified in internal medicine, pulmonary diseases, and critical care medicine.

Dr. Karl Benzio is a psychiatrist is an international presenter. He earned his MD with honors in psychiatry in 1989 from the UMDNJ-New Jersey Medical School, and completed a Psychiatric Residency at the University of California-Irvine in 1993. He is accredited by the Board of Psychiatry and Neurology. His clinical areas of expertise are Adolescence, Addictions,

and Christian populations and treatment modalities. He has directed adult and adolescent programs, psychiatric ER care, and a Christian Rehab program. His decision-making workshop “Within Reach” is used in many different addiction and mental health treatment situations. Dr. Benzio has testified before the United States Congress, the Pennsylvania House of Representatives, and the President’s Bioethics Commission. He has taught conferences in Uganda and Kenya, and led the first behavioral health training team into post-war Iraq.

The Pennsylvania Family Institute (PFI) is a non-profit research and education organization, based in Harrisburg, Pennsylvania, which focuses on public policies and cultural trends in Pennsylvania that impact families. Throughout its 20 years of existence, the Pennsylvania Family Institute has provided testimony and information to policy makers and the public on a range of issues. PFI’s expertise can aid the court because it is directly related to the issue at hand. PFI has long been an advocate for protecting the rights of the weak, particularly those who are not in a position to protect themselves, against the manipulation of others. Pennsylvania’s families and the fabric of social life is strongest when the weakest members of our society are protected. PFI has more than 30,000 families across the Commonwealth as members.

SUMMARY OF ARGUMENT

With the Health Care Agents Act (“Act”), the Pennsylvania legislature declared,

Health care necessary to preserve life shall be provided to an individual who has neither an end-stage medical condition nor is permanently unconscious, except if the individual is competent and objects to such care or a health care agent objects on behalf of the principal if authorized to do so by the health care power of attorney or living will.

20 PA. CONS. STAT. § 5462(c)(1) (emphasis added). Given that David Hockenberry was fully conscious and suffered only from pneumonia—a readily curable illness—the statutory command is clear: treatment “shall be provided.” *Id.*

Despite this provision, Appellants contend that the Act does not protect those incapacitated from birth. Br. for Appellant at 12–13. We leave the defense of this statute’s applicability to the party of record. In this brief, we argue that the Commonwealth still has a duty to protect individuals like David Hockenberry. Two principles, inherent in Pennsylvania law, should guide this Court’s determination.

(1) A guardian has no authority under the doctrine of ‘substituted judgment’ to impose his view that a person incapacitated from birth would prefer death.

Contrary to Appellants’ suggestion, this is not a case about the “fundamental right to refuse *unwanted* medical treatment.” Pet. for Permission to Appeal at 2 (emphasis added). Instead, this is a case about whether a third party can decide for a person—who was never able to express an informed view on these matters—that he should not be treated. Given the impossibility of finding a prior desire that never existed, and the high potential for abuse, there is no basis to extend the ‘substituted judgment’ doctrine to this case.

(2) Instead, a guardian must act in such a patient’s “best interests”—and any inquiry into those interests should include a strong presumption for life that can only be overcome in rare and manifestly appropriate circumstances.

As obligated by statute, a guardian must act in the patient’s “best interests.” Both the legislature and the courts have imbued this standard with a strong presumption for life. And for good reason. A strong general presumption for life undergirds millennia of law, ethics, and human experience. Specifically in the end-of-life context, states have long possessed strong interests in preserving individual lives, preventing suicide, and protecting the integrity of the medical community. While the presumption for life is not absolute, recognizing an exception in David Hockenberry’s case would be a novel and unjustified decision. As Mr. Hockenberry has been incapacitated for life, he has *never* expressed a subjective wish to discontinue life-preserving treatment. Further, Mr. Hockenberry has *never* been in a persistent vegetative state or had an end-stage medical illness. These characteristics suggest that Mr. Hockenberry’s guardians could not objectively conclude that death was in his best interests, and Appellants have offered no extraordinary proof that would demonstrate otherwise. Of equal importance is the medical fact that a refusal to treat in cases like Mr. Hockenberry’s might not even cause death; a patient might survive anyway and then be forced to suffer increased pain and disabilities as a direct result of the refusal to treat. .

Finally, the Superior Court’s conclusion is particularly warranted under the “clear and convincing” evidentiary burden that rightly attaches to a “best interests” determination regarding a life-or-death decision. A litany of courts, including the United States Supreme Court, has applied heightened evidentiary standards to approve guardian decisions far less consequential than death. The Court should adopt this standard to protect patients’ fundamental interests in life.

ARGUMENT

I. Appellants incorrectly assume that the ward's death is actually in their control, and as a result they risk even more pain and disabilities for a patient who doesn't die when his guardians refuse to give him basic treatment.

At the outset, it is important for the Court to recognize that refusal to give a patient basic care can lead, not to death, but to a patient's increased pain and disability. Certainly if a patient is denied artificially delivered food and water he or she will dehydrate to death, and in this case Appellants seek a power so broad that it would include subjecting patients like Mr. Hockenberry to such a fate at the guardian's discretion.

But Appellants also seem to assume that if guardians had the power simply not to treat recoverable illnesses like pneumonia, the result would always be death. In fact, short of allowing guardians to commit direct euthanasia, guardians and doctors do not have that kind of control over a patient's outcome. Guardians cannot ultimately prevent patients from surviving their periodic ailments if nature takes its course. And the consequences of non-treatment for surviving patients include increased suffering and exacerbated or new disabilities, all of which were completely preventable with proper treatment. Denying basic treatment to a patient with disabilities in this way is indistinguishable from committing medical neglect against any other vulnerable ward.

Out of many possible circumstances that patients regularly encounter, Amicus Curiae Doctors on this brief wish to propose the following three situations for the Court's consideration. First, consider Mr. Hockenberry's own condition in 2007 and 2008 in which he dealt with aspiration pneumonia. "Over Appellants' objection, D.L.H. remained on a mechanical ventilator for approximately three weeks, at which time his aspiration pneumonia subsided to the point where he no longer required ventilation treatment." *In re D.L.H.*, 967 A.2d 971, 974 (Pa. Super.

Ct. 2009) . Consider however that the failure to treat aspiration pneumonia might not lead to death, but to survival with injuries caused by the non-treatment. Such injuries include scarring of the lung, which can result in permanent respiratory insufficiency, which limits a patient's activity tolerance and requires oxygen supplementation. This could leave patients subject to decubitus ulcers which can be painful and cause the patient to experience recurrent infections. Scars in the lungs can predispose the patient to cavities susceptible to various fungal infections requiring long term medication with risks of side effects. On the other hand, a mere three weeks on a ventilator led to Mr. Hockenberry's complete recovery. Appellants want the power to impose painful, debilitating, and unnecessary risks on a ward, including increased rather than decreased needs for medical intervention, if they decide that his death would be preferable. These factors are extremely relevant both to the concept that the ward would "want" to choose non-treatment and risk these injuries, and that it is in the ward's best interests to unnecessarily risk such injuries.

Adverse long term health effects are not limited to withholding a ventilator. Instead, patients similar to Mr. Hockenberry can also face gastrointestinal ailments that, if not treated, can cause serious harm short of death. Many patients encounter reversible and treatable bouts of gastroenteritis (vomiting and diarrhea). If a simple treatment of intravenous re-hydration is withheld, their condition can cause permanent kidney damage. Patients also are confronted with gastrointestinal hemorrhages, either due to a bleeding peptic ulcer or diverticulosis. If treatment is withheld the patients might suffer death from acute blood loss, but might also stop short of death and instead result chronic anemia, which can in turn cause congestive heart failure.

Third, patients in long-term care frequently experience urinary tract infections. These infections can be treated with oral or intravenous antibiotics. A decision to withhold such simple

treatment, however, can cause the kidney damage and scarring, which would otherwise be preventable.

The peril of Appellants' request in this case, therefore, is not merely that death would be discriminatorily viewed as being in a disabled patient's "best interests," or would be something imposed on a patient absent any choice on his own part by the fiction of substituted judgment. Letting guardians refuse to treat their wards would empower them to recklessly risk painful and even more burdensome disabilities for the patient. Any life-sustaining treatment that Appellants want the power to remove is not merely "life-sustaining," it is also inherently injury-preventing. The withholding of such treatment must accordingly be considered as not only a choice for death, but also a deliberate subjection of a patient to the risk of serious injury. This fact more fully enlightens why the Superior Court was correct to affirm that the refusal to give basic treatment to a non-terminal patient is not in a patient's best interests, nor properly considered to be that patient's own "substituted judgment."

II. Permitting a guardian to reject life sustaining treatment on behalf of a lifelong incapacitated person on the theory of 'substituted judgment' would be a vast and unwarranted departure from the current law.

In the guise of implementing Mr. Hockenberry's "fundamental right to refuse *unwanted* medical treatment," Pet. for Permission to Appeal at 2 (emphasis added), Appellants seek to impose their view that death would be in D.L.H's best interest. Their effort can be rejected with a simple response: the disabled are better off alive than dead or than subjected to unnecessary risk of injury. *See infra* Part III. To the extent that Appellants frame their case as an attempt to preserve Mr. Hockenberry's autonomy,¹ however, their entire endeavor suffers from an even more fundamental flaw: it claims to champion Mr. Hockenberry's right to self-determination by

¹ *See id.*; *see also* Br. for Appellant at 12-14 ("Section 5462(c)(1) should not be read to deprive David of his right to choose which treatments he shall receive . . .").

allowing *someone else* to decide that he would prefer death. Neither the Constitution nor the common law bestows guardians with such unfettered power, and there is no basis—in logic or policy—to expand the law and permit such ‘substituted judgment’ for those who have been incapacitated since birth.

A. The Constitution does not give Appellants, as guardians, the right to decide that Mr. Hockenberry would prefer death.

Surrogates do not have a constitutional right to terminate life-sustaining medical care for incompetent patients. In *Cruzan v. Director, Missouri Dept. of Health*, the Supreme Court noted that a competent person generally has a right to refuse unwanted medical treatment. 497 U.S. 261, 278 (1990). The Court, however, expressly rejected the notion that “an incompetent person should possess the same right in this respect as is possessed by a competent person.” *Id.* at 279–80. Indeed, the Court emphasized that an incompetent patient cannot make an informed and voluntary choice:

The difference between the choice made *by* a competent person to refuse medical treatment, and the choice made *for* an incompetent person *by someone else* to refuse medical treatment, are *so obviously different* that the State is warranted in establishing rigorous procedures for the latter class of cases which do not apply to the former class.

Id. at 287 n.12 (emphasis added). The Court, therefore, held that a guardian has no right to refuse treatment on behalf of an incompetent patient. *Id.* at 286–87. Instead, states are free to preclude such “substituted judgment” because they wish to protect the vulnerable, or because they refuse “to make judgments about the ‘quality’ of life that a particular individual may enjoy” and “simply assert an unqualified interest in the preservation of human life.” *Id.* at 281–82. Thus, *Cruzan* forecloses any suggestion that the Constitution bestows Appellants with the power to impose their “substituted judgment.”

B. Pennsylvania law does not give Appellants, as guardians, the right to decide that Mr. Hockenberry would prefer death.

This Court’s narrow substituted judgment precedent does not extend to the present case. In *In re Fiori*, 673 A.2d 905, 912 (Pa. 1996), this Court concluded that, for those—and only those—in a persistent vegetative state, close family members could be permitted “to determine what measures the PVS patient would have desired” and implement those measures. *Id.* at 912.

To form such ‘substituted judgment,’ however,

[t]he surrogate considers the patient’s prior statements about and reactions to medical issues, all the facets of the patient’s personality that the surrogate is familiar with—with, of course, particular reference to his or her relevant philosophical, theological, and ethical values—in order to extrapolate what course of medical treatment the patient would choose.

Id. at 911 (internal citation omitted). This approach was “intended to ensure that the surrogate decision maker effectuates as much as possible the decision that the incompetent patient would make if he or she were competent.” *Id.*

This Court expressly stated that a guardian can *only* invoke this concept for once-competent patients currently in a persistent vegetative state.

We stress that the matter *sub judice* addresses only a very narrow issue: whether life-support may be terminated for a PVS patient who was once competent, but did not express desires as to medical treatment, and who may make that choice. It would be unwise for us to speak to alternate scenarios that are not now before us. Thus, we explicitly note that our holding today applies only to situations where the individual in question was once a competent adult, but is now in a permanent vegetative state, and while competent that individual left no advance directives pertaining to life sustaining measures.

Id. at 913. Indeed, this Court explicitly said that its decision did not apply “where there is no basis to make a substituted judgment.” *Id.* at 912, n.11.² Thus, contrary to Appellant’s

² At least for those who were once-competent, the legislature has resolved this issue. *See* 20 PA. CONS. STAT. § 5456(c)(5)(ii) (stating that where the patient’s subjective wishes are unclear, life

suggestion, *In re Fiori* does not establish that a guardian can decide—on behalf of someone who has never been able to speak for himself—that a patient would prefer death.

C. The extension of a ‘substituted judgment’ standard to those who were incapacitated since birth would be a cruel charade.

Under the pretense of vindicating a patient’s right to self-determination, the ‘substituted judgment’ doctrine that Appellants argue should apply in this case would permit a third party to decide that the patient would prefer death over life. Even when applied to those who were once competent, this pretense raises disturbing issues. The doctrine is a legal fiction in that it purports to impose the decision of a patient who concededly is not competent and cannot express his desires. Yet it imposes irrevocable life-and-death decisions that are fraught with guesswork. And instead of compensating for its precariousness, the doctrine appeals to the rhetoric of “rights” so that it shields from scrutiny the decision by a court—or even a guardian acting on his own—to end a patient’s life. Judges and guardians acting under the cover of the patient’s “rights” “do not have to put the utilitarian analysis down on paper; they do not have to say things about the incompetent that no one wants to say: things reflecting an attitude that the incompetent is something less than a person—or something less than alive.” Louise Harmon, *Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1, 61 (1990). The substituted judgment doctrine instead permits guardians to cloak a decision to dispose of an incompetent in the language of autonomy and rights, speculate as to what the patient’s true desires would be, and leave the basis for their decision hidden in the dark.³

sustaining treatment decisions must be made in the ward’s best interests).

³ For a comprehensive criticism of the concept, see Walter Weber, *Substituted Judgment Doctrine: A Critical Analysis*, 1 ISSUES L. & MED. 131, 151 (1985):

The fundamental defect of substituted judgment doctrine is that it claims to be something other than what it is. Its attractive language proclaims the vindication

As troubling as the substituted judgment doctrine's problems are in general, they pale in comparison to its incoherence when applied to those who—like David Hockenberry—were never competent. Extending the doctrine to such cases would press the doctrine beyond its theoretical breaking point. “Most courts, when asked to apply substituted judgment to an infant or to a profoundly disabled adult, have rejected the idea as involving an unrealistic or ‘impossible’ task.” See Norman Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 ANNALS OF HEALTH LAW 37, 42 (2004).⁴ This is because the whole aim of “substituted judgment” is to implement the informed decision that the patient would have made while competent, based on the patient's previously articulated values, preferences, and expressions. A person with profound mental disabilities from birth has never been able to make an informed decision; therefore, even as a theoretical matter, there is no “choice” to vindicate.⁵

The problems with extending the ‘substituted judgment’ doctrine to cases like this one are not merely theoretical. Permitting such unfettered decision-making on behalf of people who are incapacitated from birth would expose them to even greater potential for abuse than they already face. Such abuse might, of course, stem from prejudice or utilitarian concerns. Critically, though, abuse could also stem from honest misperceptions about the quality of the life of a person with disabilities. When attempting to adopt an incompetent person's point of view,

of important personal rights, but, in operation, it serves as merely another method of deciding what to do with helpless incompetents. The appealing rhetoric makes it an especially potent decisional instrument; meanwhile this same rhetoric largely shields the outcome from criticism.

⁴ See, e.g., *Lenz v. L.E. Phillips Career Dev. Ctr. (In re Guardianship of L.W.)*, 482 N.W.2d 60, 78 (Wis. 1992).

⁵ The process “appears more an exercise in fictional characterization than an enhancement of rights.” Walter Weber, *Substituted Judgment Doctrine: A Critical Analysis*, 1 ISSUES L. & MED. 131, 146 (1985).

no one can completely abandon his own perspective on life with handicaps. Yet “[m]any a person has imagined that death would be preferable to a certain illness, deformity, or disability, only to find an unsuspected capacity to deal with the handicap when it eventuates.” Walter Weber, *Substituted Judgment Doctrine: A Critical Analysis*, 1 ISSUES L. & MED. 131, 146 (1985).⁶ Throughout this country’s history, people with disabilities have had to fight against such stereotypes about the quality of their lives. *See infra* Part IV. Endorsing “substituted judgment” here would only open another front in this battle.

D. The few cases that extend ‘substituted judgment’ to lifelong incompetents demonstrate its perils.

The seminal case extending ‘substituted judgment’ to a person incapacitated from birth highlights the incoherence and injustice of applying it against persons with lifelong incapacitating disabilities. In considering the fate of Joseph Saikewicz—a 67-year old man retarded from birth who had recently been diagnosed with leukemia—the Supreme Court of Massachusetts conjured into existence a competent Mr. Saikewicz and let him “decide” that he did not want treatment that the vast majority of people would desire.⁷ *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417, 430–32 (Ma. 1977). Even though chemotherapy offered a 30 to 50 percent chance of putting Saikewicz’s cancer in remission, the court allowed his guardians to reject the treatment based in part on “the future incompetency of the individual,” in other words, based on the fact that if he survived he would still have his disability. *Id.* at 431. The fictional Mr. Saikewicz chose death; and two months later, the real Mr. Saikewicz died.

⁶ See also Martha A. Field, *Killing “The Handicapped”—Before and After Birth*, 16 HARV. WOMEN’S L.J. 79, 87-88 (1993) (“One problem with the quality-of-life arguments is that very often they are based upon prejudice against the handicapped, and even more often they are based upon ignorance about the handicapped . . . Even when acting in total good faith, parents and judges will often project onto the [ward] their own horror of handicap.”).

⁷ His own desire in the matter, while not binding, was not clear. *Id.* at 731.

Saikewicz underscores the perils of transferring “substituted judgment” to these types of cases.⁸ It highlights the troubling fiction of discerning the “informed decision” of someone who had never been competent, and the injustice of assuming that a handicapped person, because of his disability, would not fight for life when the vast majority of able-bodied persons would. As one commentator put it,

We let Joseph Saikewicz die because that was what the Joseph Saikewicz puppet said he wanted With the doctrine of substituted judgment, the raw truth is this: The judge is in control of the incompetent, and with that control comes an obligation—an obligation to protect the incompetent”

Louise Harmon, *Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1, 71 (1990).

Patients can be protected without allowing guardians to implement their ‘substituted judgment’ to choose death on behalf of those incapacitated from birth. As discussed below, the Commonwealth already applies a patient’s best-interests as the standard used for medical decisions. The standard has a strong presumption in favor of life, and therefore it does not allow persons with disabilities to be considered better off dead because they are disabled, or to have their life with a disability be considered a burden that death by non-treatment may legitimately relieve. Nevertheless, by the best interests standard the Commonwealth still ensures that a patient’s interests in comfort and pain relief can be protected alongside their right to be considered worthy of life, and that he need not be subjected to burdensome interventions that provide no medical benefit.

⁸ See also Martha A. Field, *Killing “The Handicapped”—Before and After Birth*, 16 HARV. WOMEN’S L.J. 79, 88, n.27 (listing articles criticizing the use of ‘substituted judgment’ to refuse treatment on behalf of another group who never had an opportunity to speak for themselves: infants born with disabilities).

III. The guardians must act in D.L.H’s “best interests,” which naturally and by law include a strong presumption for life.

Under Pennsylvania law, a guardian may only act in the ward’s best interests. 20 PA. CONS. STAT. § 5521(a) (“It shall be the duty of the guardian of the person to assert the rights and best interests of the incapacitated person.”). Similarly, where the patient’s subjective wishes are unclear, health care agents (or the Commonwealth by default) may only make life-sustaining treatment decisions in the ward’s best interests. 20 PA. CONS. STAT. § 5456(c)(5)(ii). Through these statutory commands, the Pennsylvania legislature has affirmed that all people under the care of a guardian—whether for end-of-life care or otherwise—are entitled to care in their best interests. This “best interests” standard entails a strong presumption for life—a presumption that, in cases involving those incapacitated from birth, can only be overcome by clear and convincing evidence to the contrary.

A. A patient’s best interests are now and have always been marked by a strong presumption for life.

By way of both law and common humanity, a patient’s “best interests” inherently includes a strong presumption for the preservation of life. The Guardian statute does not independently define “best interests,” but both the Health Care Agents and Representatives Act and Pennsylvania common law provide the definition.⁹ In Pennsylvania, the “best interests” standard is objective:

- (A) The *preservation of life*.
- (B) The relief from suffering.
- (C) The *preservation or restoration of functioning*, taking into account any concurrent disease, illness or physical, mental, cognitive or intellectual condition

⁹ Cf. *In re D.L.H.*, 967 A.2d at 981 n.4 (“[T]he Act and the authority of a health care agent informs our understanding of the extent to which a guardian possesses ‘plenary’ power.”).

that may have predated the principal's end-stage medical condition. 20 PA. CONS. STAT. § 5456(c)(5)(ii)(A) to (C) (emphasis added). *See also In re Fiori*, 673 A.2d 905, 912 n.11 (Pa. 1996) (noting that the best interests standard requires consideration of “the patient’s relief from suffering, the preservation or restoration of functioning, and the quality and extent of sustained life.”). These textual descriptions of “best interests” manifest a strong presumption for life. *See also* 20 PA. CONS. STAT. § 5462(c)(1) (“Health care necessary to preserve life shall be provided to an individual who has neither an end-stage medical condition nor is permanently unconscious, except if the individual is competent and objects to such care or a health care agent objects on behalf of the principal if authorized to do so by the health care power of attorney or living will.”); 20 PA. CONS. STAT. § 5456(c)(5)(iii)(A) (absent specific, written authorization by the patient, “a health care agent shall presume that the principal would not want nutrition and hydration withheld or withdrawn”).

These Pennsylvania sources are commensurate with the strong presumption for life undergirding millennia of law, ethics, and human experience. If any single fact is true about human beings in general, it is that they prefer life to death. It is humane common sense to affirm that a person’s overarching “best interests” naturally include a strong presumption for life. Even more so, our nation and civilization are rife with legal, ethical, and historical affirmations of this basic human posture. *See* HIPPOCRATIC OATH (“I will prescribe regimens for the good of my patients according to my ability and my judgment and *never do harm to anyone.*”) (late 5th century B.C.) (emphasis added); THE DECLARATION OF INDEPENDENCE pmb. (U.S. 1776) (highlighting “certain unalienable Rights, that among these are Life”); U.S. CONST. amend. V (“nor be deprived of life”); U.S. CONST. amend. XIV, § 1 (“nor shall any state deprive any person of life”); PA. CONST., art. I (“All men . . . have certain inherent and indefeasible

rights, among which are those of enjoying and defending life . . .”); *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 280 (1990) (affirming that for the protection and preservation of human life, “there can be no gainsaying this interest”); J. MILLER, HANDBOOK OF CRIMINAL LAW 251 (1934) (“One of the greatest obligations of organized governments is the preservation of human life.”).

This general presumption corresponds with the Commonwealth’s overarching interest in protecting life for the most vulnerable. 20 PA. CONS. STAT. § 5423(c)(2) (affirming society’s interest in the “preservation and protection of human life”). Even for the medically ill at the close of life, this Court has specifically affirmed the venerable state interests in preserving life as including the “1) protection of third parties; 2) prevention of suicide; 3) protection of the ethical integrity of the medical community; and 4) preservation of life.” *In re Fiori*, 673 A.2d at 910 (calling the preservation of life the “most significant” interest). Particularly for such individuals, it bears emphasis that only the *patient’s* “best interests” are at issue, not the “value that others find in the continuation of the patient’s life” or the decision-maker’s opinion of the quality of that life. *In re D.L.H.*, 967 A.2d 971, 983 (Pa. Super. Ct. 2009) (quoting *Woods v. Commonwealth*, 142 S.W.3d 24, 34 (Ky. 2004)).

B. This presumption can be overcome in certain limited circumstances—none of which exist here.

Strong as it is, the presumption for life is not absolute, and it can be overcome in certain limited circumstances. In two clearer scenarios not presented in this case, a competent patient could expressly elect to decline further medical treatment, or a guardian or agent could rely on an unconscious or incompetent patient’s previously expressed subjective wishes regarding end-of-life care. *Fiori* considered the second of these scenarios when it held that the decision-maker could properly withdraw life-preserving treatment. 673 A.2d 905, 912 (Pa. 1996).

But, as discussed above, *Fiori*'s logic does not apply when considering a never-competent patient who did not, by definition, competently express subjective wishes (and therefore whose wishes cannot be extrapolated via "substituted judgment"). In that case, it is necessary to apply an *objective* test of the rights and best interests. 20 PA. CONS. STAT. § 5456(c)(5)(ii). An objective analysis acknowledges that in rare and exceptional circumstances it may be possible that a person's best interests are inconsistent with preserving life at all costs.¹⁰ But in any objective analysis, it is unjust to *presume* that death—withdrawing a patient's basic human needs of nutrition and medical care—is consistent with the patient's "rights and best interests."

The case before the court requires application of this objective best interests test for determining whether death (or survival with exacerbated injury due to the treatment withdrawal) is in Mr. Hockenberry's best interests. First, it is impossible to apply any other test because the patient has never been able to express his views. Second, unlike in *Fiori*, Mr. Hockenberry has never been in a persistent vegetative state nor did he ever suffer from an end-stage medical illness. Therefore, no exceptional medical circumstance suggests facts that the Court has used to justify withdrawal of treatment.

Absent these two controlling factors, there would have to be "extraordinary" evidence to counsel against treating a patient. *In re D.L.H.*, 967 A.2d at 983. Refusing to treat such a patient not only assumes that death is preferable to life because of a patient's disability, it also allows guardians to risk pain, injury, and further disabilities to a patient who may well survive. It is

¹⁰ See 20 PA. CONS. STAT. § 5456(c)(1)-(3) (requiring a health care agent for patient with an end-stage illness to gather treatment information that distinguishes between curative alternatives, palliative alternatives, and alternatives which will merely serve to prolong the process of dying); *id.* at (c)(5)(ii) (requiring health care agent for such a patient to consider the patient's relief from suffering, as well as the preservation or restoration of functioning, in determining appropriate treatment).

very difficult to conceive how such intentional neglect is in any patient’s best interests. As the court below persuasively reasoned, it would be an irrational and absurd conclusion that a plenary guardian possesses “blanket authority to decline life preserving medical treatment on behalf of D.L.H. . . .” *Id.* at 981 (“It is presumed that the legislature did not intend an absurd or unreasonable result. In this regard, we are permitted to examine the practical consequences of a particular interpretation.” (internal brackets omitted)). If an individual’s fundamental right to life, liberty, or property “depends on the outcome of no election,” that right may certainly not depend on the choice of one person. *Palmer v. Thompson*, 403 U.S. 217, 234 (1971).

C. Pennsylvania appropriately requires “clear and convincing evidence” to displace such an individual’s strong presumption for life.

The court below persuasively followed the Guardian statute and a litany of common law precedents to require “clear and convincing evidence” before a guardian could find that death constituted a ward’s best interests. Rather than granting *carte blanche* authority to guardians, the Pennsylvania legislature has directed that, even on matters less consequential than death, the guardian must make a sufficient evidentiary showing to the court before proceeding. *See* 20 PA. CONS. STAT. § 5521(d) (requiring court authorization before a guardian provides consent for the ward on less-consequential matters than death including, *inter alia*, abortion, sterilization, psychosurgery, divorce, or experimental biomedical procedures); 20 PA. CONS. STAT. § 5521(f) (forbidding the court to authorize a guardian to, *inter alia*, admit the ward to a psychiatric facility or relinquish his parental rights). Courts, like the one below, have consistently found that safeguarding patients requires a clear and convincing evidence standard for a guardian to conclude that death is in the patient’s best interests. The United States Supreme Court held in *Cruzan*, for example, that it is permissible for a state to require “clear and convincing evidence” before withdrawing life sustaining treatment for an incapacitated individual—even for the harder

case where a person is in a persistent vegetative state. *Cruzan*, 497 U.S. at 280 (“We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements.”).

Where the guardian—rather than the patient herself—ultimately asserts the belief that death or the risk of survival with pain and injury actually effectuates the patient’s best interests, a showing of clear and convincing evidence serves as the minimally appropriate safeguard.

“[S]uch a standard of proof is necessary in a case such as this one, where a fundamental right is concerned” *In re Matter of Terwilliger*, 450 A.2d 1376, 1382 (Pa. Super. Ct. 1982) (affirming use of a “clear and convincing” evidence standard for a guardian’s request to sterilize his ward, a “permanent termination of . . . [an] intensely personal right”). *See also Wendland v. Wendland*, 28 P.3d 152, 175 (Cal. 2001); *In re Martin*, 538 N.W.2d 399, 410 (Mich. 1999); *Spahn v. Eisenberg*, 543 N.W.2d 485, 491–92 (Wis. 1997); *DeGrella v. Elston*, 858 S.W.2d 698, 706 (Ky. 1993); *Mack v. Mack*, 618 A.2d 744, 753 (Md. 1993); *Cruzan v. Harmon*, 760 S.W.2d 408, 427 (Mo. 1988); *In re Westchester Med. Ctr.*, 531 N.E.2d 607, 611 (N.Y. 1988) (noting that it would be “unacceptable” to remove an incapacitated patient from life support without clear and convincing evidence that the patient had chosen such a course while still competent); *In re D.L.H.*, 967 A.2d 971, 983 (Pa. Super. Ct. 2009) (calling the appropriate burden “extraordinary”).

Affirming the clear and convincing evidentiary standard not only effectuates procedural safeguards, it can additionally promote and protect certain underlying societal interests.

We think it self-evident that the interests at stake in the instant proceedings are more substantial, both on an individual and societal level, than those involved in a run-of-the-mine civil dispute. But not only does the standard of proof reflect the importance of a particular adjudication, it also serves as a societal judgment about how the risk of error should be distributed between the litigants.

Santosky v. Kramer, 455 U.S. 745, 756 (1982) (requiring at least “clear and convincing evidence” for severing a parents’ rights in their natural child). Additionally, irreparable decisions implicating life and death are precisely the matters that warrant heightened procedural protections to ensure the accuracy of the guardian’s decision. *See Cruzan*, 497 U.S. at 282. A clear and convincing evidence standard is the appropriate level of scrutiny to ensure that courts decide these issues of life and death correctly. Even more so than in sterilization or severance of parental ties cases, when a guardian elects to remove life-sustaining treatment for an individual and risk death or further harm, the guardian is not only acting against that individual’s presumption for life but is acting with irreversible finality.

Courts already regularly apply this intermediate standard for less consequential decisions than death. *Cruzan*, 497 U.S. at 282 (quoting *Santosky v. Kramer*, 455 U.S. 745, 756 (1982)). Indeed, the United States Supreme Court has mandated this standard whenever “the individual interests at stake in a state proceeding are both particularly important and more substantial than mere loss of money.” *Id.* (internal quotation marks omitted). *See Santosky v. Kramer*, 455 U.S. 745 (1982) (termination of parental rights proceedings); *Addington v. Texas*, 441 U.S. 418 (1979) (civil commitment proceedings); *Woodby v. INS*, 385 U.S. 276 (1966) (deportation proceedings); *Schneiderman v. United States*, 320 U.S. 118 (1943) (denaturalization proceedings). *A fortiori*, the clear and convincing evidence standard should apply to a decision of life and death. State courts have already been applying this standard to approve the removal of life-sustaining treatment by a ward’s guardian in persistent vegetative state cases. *See Mack v. Mack*, 618 A.2d 744, 754–55 (Md. 1993) (citing cases). Where such scrutiny is required even for non-responsive PVS individuals, it would be anomalous and unjust to posit some lesser standard for a lifelong incapacitated individual who is *not* in a PVS or end-stage medical illness.

Recognizing these principles, the court below described a workable and adequately protective clear and convincing evidence standard before a guardian is permitted to conclude that the “best interests” of a patient is death (or treatment withdrawal that risks injury upon survival). The court required the following *minimum* showing: reliable expert medical testimony regarding a “severe, permanent medical condition” and regarding the patient’s state of deterioration and pain. *In re D.L.H.*, 967 A.2d at 984. This Court should affirm that these showings are indeed required and that the burdens of production and persuasion lie with the moving party. As the lower court required, the court must be “definitively convinced” that the interest in life is “markedly outweighed” by the patient’s severe and permanent condition and suffering. *Id.* A court will only affirm lethal treatment withdrawal when it can conclude “without hesitation” that treatment would amount to “an inhumane act that runs so contrary to basic notions of fundamental decency.” *Id.*

Living with a disability does not count as an “inhumane act.” The fact that a patient has long-suffered from what completely healthy people would consider difficult disabilities or hardships does not cause a patient’s best interests to encompass a lack of treatment that risks death or further injury upon survival. *Id.* See *In re Conroy*, 486 A.2d 1209, 1233 (N.J. 1985) (“The mere fact that a patient’s functioning is limited or his prognosis dim does not mean that he is not enjoying what remains of his life or that it is in his best interests to die.”). As the lower court concluded, the outcome of this inquiry is not difficult for David Hockenberry, but the ease of the inquiry here must not diminish the need for a rigorous and clearly articulated test that ensures the protection of the preservation of life in future cases. The standard applied in this case is widely accepted and appropriate.

IV. Refusing Mr. Hockenberry life-preserving treatment would represent the step down the “slippery slope” that disability-rights groups have long feared.

If a court or guardian believes that death is in a patient’s best interests, the “‘right to die’ could become a license to kill.” *In re Guardianship of Browning*, 543 So.2d 258, 269 (Fla. App. Ct. 1989). This is precisely why disabilities-rights groups, fearing a slippery slope, have long resisted the notion of a right to die.¹¹ To allow a guardian to find that death is in the “best interests” of a patient with disabilities—or worse, that the incapacitated patient would fictionally choose it himself—would signal an arrival at the bottom of this slope that these groups have long feared.

This fear is justified by a long history of discrimination against the disabled, including medical discrimination. As the Supreme Court has acknowledged, “[T]hrough ignorance and prejudice the mentally retarded have been subjected to a history of unfair and often grotesque mistreatment.” *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432, 454 (1985) (Stevens,

¹¹ In *Vacco v. Quill*, 521 U.S. 793, 804 (1997), and *Washington v. Glucksberg*, 521 U.S. 702, 722-28 (1997)—both involving a challenge to a ban on assisted suicide—disability groups opposed the notion of a right to die. See Richard E. Coleson, *The Glucksberg & Quill Amicus Curiae Briefs: Verbatim Arguments Opposing Assisted Suicide*, 13 ISSUES IN L. & MED. 1, 6 & n.13 (1997) (citing the National Legal Center for the Medically Dependent and Disabled, Inc., Disabilities Perspectives; the Ethics and Advocacy Task Force of the Nursing Home Action Group; the Michigan Handicappers Caucus; a group of other individuals with terminal conditions or other disabilities; the National Catholic Office for Persons with Disabilities, the National Spinal Cord Injury Association; and Not Dead Yet and Americans Disabled for Attendant Programs Today). In the litigation surrounding Terri Schiavo disability-rights groups again vehemently opposed a decision to withdraw life-sustaining treatment. Indeed, twenty-one disability-rights groups signed a letter supporting Schiavo’s continued feeding. See ADA Watch *et al.*, *Terri Schindler-Schiavo and Disability Rights*, available at <http://www.thearlink.org/news/article.asp?ID=623>. These groups expressed deep concern that terminating Schiavo’s life reflected a decision that “some deaths are more rational than others and that incompetent ill and disabled people do not deserve the same type of health care that “competent” people would receive.” *Id.*

J., joined by Burger, C.J., concurring). The eugenics movement has led to many infamous examples of discrimination such as the involuntary sterilization of the mentally disabled.¹²

This history of discrimination makes a substituted judgment standard—or a loose, inherently anti-disability inquiry into a disabled person’s best-interests—a frightening prospect.

More than one court has noted that these judgments are “rife with the potential for abuse.”

DeGrella v. Elston, 858 S.W.2d 698, 711 (Ky. 1993) (Lambert, J., concurring). And as the Ninth Circuit panel observed in *Compassion in Dying v. Washington*, “[w]hen the nondisabled say they want to die, they are labeled as suicidal; if they are disabled, it is treated as ‘natural’ or ‘reasonable’.” 49 F.3d 586, 592–93 (9th Cir. 1995).¹³ Further, the Supreme Court has repeatedly recognized the danger that the right to die poses to the disabled. *See Glucksberg*, 521 U.S. at 732 (“[I]legalizing physician-assisted suicide would pose profound risks to many individuals who are ill and vulnerable The risk of harm is greatest for the many individuals in our society whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, advanced age, or membership in a stigmatized social group.” (internal citation omitted)).

This case presents the bottom of this slippery slope. Unlike patients in previous cases involving the right-to-die and the refusal of life sustaining treatment, David Hockenberry neither suffers from a terminal illness nor is permanently unconscious. Nonetheless, Mr. Hockenberry’s guardians decided that death by asphyxiation, or the risk of exacerbated injuries if he survived, were in his “best interests,” though he suffered from nothing more than a case of pneumonia that he quickly recovered from with a ventilator. To allow guardians to refuse life-sustaining

¹² *Buck v. Bell*, 274 U.S. 200, 207 (1927) (Holmes, J.) (“Three generations of imbeciles are enough.”).

¹³ *Compassion in Dying* was reversed by an en banc decision of the 9th Circuit—a decision which the Supreme Court, in turn, reversed. *Compassion in Dying v. Washington*, 49 F.3d 586, 591 (9th Cir. 1995), *rev’d en banc*, 79 F.3d 790 (9th Cir. 1996), *rev’d sub nom. Washington v. Glucksberg*, 521 U.S. 702, 722-28 (1997).

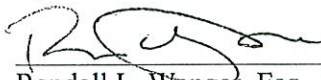
treatment in the name of such a patient's best interests would represent a radical and deadly advance for discrimination against persons with disabilities.

CONCLUSION

Amici curiae respectfully request this Honorable Court to reject Appellants' petition to serve as Health Care Agents for David Hockenberry and to affirm the court below.

Respectfully submitted this 15th Day of March, 2010

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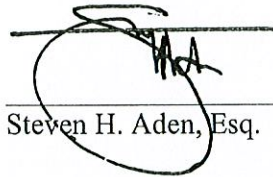
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I hereby certify that I am this day serving two copies of the foregoing document upon each of the persons below, by First Class Mail, which service satisfies the requirements of Pa.

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