INTRODUCTION

The University of Houston annually hosts the Moot Court National Championship (MCNC), an invitation only tournament that sees the best teams from across the country competing head to head over a wide variety of current legal issues. The topic for the 2010 MCNC dealt with a dispute based on end of life decision making and the myriad state and federal issues implicated when the most fundamental questions of healthcare are involved. The Houston Journal of Health Law and Policy is proud to present the arguments from the Best Brief of the 2010 competition, submitted by Chicago Kent School of Law. While this specific case may not be real, the issues are of great concern to the legal profession, especially those of us concerned more directly with healthcare and the policies that drive it.

2010 Moot Court National Championship Best Brief

No. C09-0115-1

In The

Supreme Court of the United States

OCTOBER TERM, 2009

MICHELLE KELLER & NEW AMSTERDAM GENERAL HOSPITAL

Petitioners,

-v.-

TYLER & FLORENCE KELLER

Respondents.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE FOURTEENTH CIRCUIT

Brief by Laura Elkayam, Chloe Long, and Vincent Smolczynski of Chicago-Kent School of Law

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QUESTIONS PRESENTED

I. Abstention is proper when a case presents a difficult question of state law of substantial public importance or federal review risks disruption of a complex state scheme. Did the Fourteenth Circuit Court of Appeals err in reversing the District Court's Order of Abstention where this case implicates sensitive questions of New Amsterdam's procedures governing the withdrawal of life-prolonging medical treatment, and where New Amsterdam has a sophisticated and developing system for effectuating its citizens' preferences on end-of-life decision-making?

II. Competent persons possess a liberty interest in determining, on their own behalf, whether to continue life-prolonging medical treatment. Is it permissible under the Fourteenth Amendment to deny this liberty interest to a minimally conscious individual that is unable to understand, appreciate or rationalize information regarding his medical circumstances?

OPINIONS BELOW

The opinion of the United States District Court for the Eastern District of New Amsterdam is located on page 12 of the Record. The opinion of the United States Court of Appeals for the Fourteenth Circuit is located on page 3 of the Record. Publication in the Federal Reporter is pending.

CONSTITUTIONAL AND STATUTORY PROVISIONS INVOLVED

U.S. Const. Amend. XIV, § 1: "No state shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any state deprive any person of life, liberty, or property without due process of law..."

New Amsterdam Prob. Code § 294.60: Reproduced in Appendix "C"

STATEMENT OF THE CASE

Steven Keller ("Steven"), a New Amsterdam city firefighter, has suffered a massive and debilitating head trauma from which there is no hope of recovery. (R. 5-6.) Now, Michelle Keller ("Michelle"), his wife, seeks to fulfill Steven's wishes by removing him from life-prolonging medical treatment and allowing him to die a natural and dignified death. (R. 9.)

Steven's accident and diagnosis

On December 22, 2008, Steven suffered extensive head trauma and internal injuries when a ceiling collapsed on him while he was on-duty fighting a fire in a local office building. (R. 5.) Steven was unconscious when he arrived at the hospital; doctors immediately placed him in a medically-induced coma in order to treat his extensive burns and severe internal injuries. (R. 6.) While in this sixmonth-long coma, Steven received numerous medical treatments, including intravenous feedings, surgeries, skin grafts, and transfusions. (R. 6.) These treatments alone cost over \$350,000. (R. 6.)

When doctors finally revived Steven from his coma in July 2009, Steven entered into a minimally conscious state ("MCS"), in which he has remained since. (R. 6.) In this state, Steven's abilities are limited to primitive reflexes, occasionally following simple commands, and rarely and unpredictably nodding or shaking his head when asked simple yes-or-no questions; the accuracy of these responses is uncertain. (R. 6.) Steven's doctors and three independent neurologists agree that the MCS diagnosis sentences Steven to a life in which there is no hope of regaining full neurological function. (R. 6.) Additional costly surgeries are inevitable and will cause Steven great pain for the rest of his life, a life that could continue on in this manner for days, months or years. (R. 6.) Steven will likely remain hospitalized until his death. (R. 6.)

Doctors propose three options: 1) prolong Steven's life indefinitely through the use of feeding technology and other treatments; 2) refrain from treating Steven's infections and allow him to succumb to the resulting illnesses; or 3) allow Steven to die naturally by withdrawing the artificial nutrition and hydration technologies that currently prolong his life. (R. 6-7.)

Steven's past expressions of his medical preferences

Fortunately, Steven provided guidance for this decision. Before the accident, Steven expressed his medical preferences, both formally and informally, should he ever confront such a dire situation. (R. 7-8.) When he first entered the fire department, he completed the "New Amsterdam Directive to Physicians and Family or Surrogates" ("the Directive"), attached as Appendix "A". (R. 7.) Steven indicated he wants life-prolonging technology withdrawn should he suffer from a coma or persistent vegetative state, such that he is unable to care for himself or make decisions. (R. 28.) Steven designated Michelle as his Medical Power of Attorney ("POA") after their engagement, though his father was the original designee. (R. 7.)

Steven also informally expressed his wishes regarding these medical preferences. (R. 7-8.) Steven's friends recall discussing the matter with Steven at the fire station during the Terri Schiavo case. (R. 8.) His friends remember Steven clearly stating that he would never want to "live like that" nor be a "burden." (R. 8.) His friends agree that Steven, who took pride in his health and thrived on physical work, would not want to waste away in a hospital bed. (R. 7.)

Michelle's effort to effectuate Steven's wishes

Michelle and Steven began dating in 2004 and have been happily married since 2007. (R. 4-5.) Together, they have a one-year-old son, Steven, Jr. (R. 5.) As Steven's wife, Medical Power of Attorney, and statutory proxy, Michelle assumes the unthinkable task of effectuating Steven's wishes. *See* (R. 4, 7, 31.) After consulting numerous medical specialists and weighing the options, Michelle determined that Steven would not want to live in an irreversible MCS. (R. 8.) She now seeks to withdraw the life-prolonging technologies to afford Steven a quick and gentle death. (R. 8.)

Tyler and Florence Keller, Steven's parents and Respondents herein, swiftly sought to thwart Michelle's decision. (R. 8.) Estranged from their son for years, Tyler and Florence reappeared in Steven's life after the accident. (R. 8.) They now claim that withdrawing life-prolonging technologies would violate Steven's fundamental religious beliefs, notwithstanding Steven's statements to the contrary and the fact that Steven no longer attends religious services. (R. 8.)

On August 10, 2009, Michelle received the final medical confirmation of the irreparability of Steven's condition, and thereafter instructed doctors to enforce the Directive. (R. 8.)

State Court rulings, and the subsequent nation-wide spectacle

Steven's parents immediately sought judicial intervention. (R. 8.) On August 10, 2009 Tyler and Florence sought an injunction from The New Amsterdam County Probate Court No. 231 ("probate court") to prevent the removal of life-prolonging technologies. (R. 8-9.) The probate court granted the injunction, on August 13, 2009, holding that Steven is able to express a preference as to whether his life-prolonging treatment should be discontinued. (R. 10.) The probate court relied primarily on a videotape in which Steven shakes his head after Florence asks him, "[w]ouldn't you rather come home with us or do you want to die?" (R. 9-10.) A full transcript of the video is attached as Appendix "B".

Michelle immediately appealed to the New Amsterdam Supreme Court ("NASC"). (R. 11.) On August 31, 2009, the NASC, sitting *en banc*, reversed the probate court and revoked the injunction. The court held that a MCS is sufficiently similar to a PVS, thus allowing Steven's Directive to apply. (R. 11.) The court questioned the videotape's probative value given the ambiguities of the questions posed to Steven. (R. 11.)

Steven was instantly thrust into the national spotlight. (R. 11.) The video that his parents entered into evidence has been viewed over five million times on the internet. (R. 11.) There has been extensive coverage of the issue on cable and network news channels. (R. 11.)

The New Amsterdam state legislature passed "The Steven Keller Act" in direct response to the NASC ruling. (R. 11-12.) Currently, New Amsterdam Probate Code § 294.60 ("§ 294.60"), which is attached as Appendix "C", mandates proxy decisions for patients who are "incapacitated or developmentally disabled." §294.60(1). The Steven Keller Act attempts to modify this legislative scheme by providing a distinct evidentiary standard for patients in a MCS, who would otherwise qualify as "incapacitated or developmentally disabled." (R. 11-12.) The legislature awaits Governor Bourdain's signature on the Act. (R. 12.)

Steven's parents solicit the federal judiciary

On September 1, 2009, Tyler and Florence filed suit in the Eastern District of New Amsterdam ("district court"), claiming that pursuant to the Fourteenth Amendment, Steven has a fundamental liberty interest in deciding, on his own behalf, whether to continue life-prolonging treatment while in this MCS. (R. 12.) Although the district court originally granted the injunction on September 20, 2009, it ultimately abstained from the matter given the substantial risk that any federal decision would impair New Amsterdam state law and policy. (R. 12.) Steven's parents again appealed, to the Fourteenth Circuit Court of Appeals ("Fourteenth Circuit"). (R. 12.)

The Fourteenth Circuit, over dissent, held that federal courts should not abstain from this issue and further held that a person has a liberty interest in determining the extent of life-prolonging procedures while in a MCS. (R. 4.) Michelle filed a writ for certiorari, which was timely granted by this Court. (R. 2.)

SUMMARY OF THE ARGUMENT

I. The Fourteenth Circuit erred in failing to uphold the District Court's abstention order. The District Court properly abstained because a federal court, sitting in equity, should decline to exercise its jurisdiction when timely and adequate state court review is available to the litigants and either: (A) the case presents difficult questions of state law bearing on policies of substantial public importance; or (B) the exercise of federal review will disrupt state efforts to establish a coherent policy with respect to a matter of substantial public concern. Timely and adequate review is available to Respondents because they may still appeal to this Court the decision of the NASC, rather than raising an entirely new constitutional claim in federal district court.

Abstention is proper because this case presents difficult questions of New Amsterdam law bearing on policies of substantial public importance. First, the federal government has traditionally left the laws governing end-of-life decisions to the states and the states consistently regulate all aspects of these decisions. Second,

these questions are difficult because their resolution involves non-legal complexities of medical science and local realities which fluctuate between the citizenry of the different states based upon ideological beliefs and cultural backgrounds. Additionally, these questions are difficult because the NASC has yet to interpret § 294.60 with respect to MCS patients, leaving the relevant state law unsettled and unclear. Finally, this case implicates policies of substantial public importance because every New Amsterdam citizen stands to be subject to New Amsterdam's end-of-life decision-making regulations, which will be considerably reshaped by this ruling.

Abstention is also proper because the exercise of federal review will disrupt state efforts to establish a coherent policy with respect to a matter of substantial public concern. New Amsterdam's existing framework for making end-of-life decisions is comprehensive and complex - it provides for extra-judiciary capacity determinations, the use of Advance Directives, and surrogate decision-making under § 294.60. New Amsterdam allows these determinations to be reviewed by its probate courts, which possess the specialized knowledge necessary for the resolution of these issues. Further, New Amsterdam's efforts to regulate end-of-life decisions are on-going. The state legislature has recently passed the Steven Keller Act that, if signed into law, will update this scheme with specific provisions for minimally conscious individuals. Federal review of the question presented here will disrupt these state efforts to implement an effective regulatory regime for end-of-life decisions.

II. Even if the District Court improperly abstained, Steven nevertheless does not possess a liberty interest in determining, on his own behalf, whether to withdraw life-prolonging medical treatment. First, Steven does not acquire this interest merely because he is conscious. Only competent persons have a constitutionally protected liberty interest in deciding whether to withdraw life-prolonging treatment. This court and lower federal and state courts have not deviated from this standard. Basing this liberty interest on consciousness, rather than competence, would flood the courts with litigants seeking judicial diagnoses of minimal consciousness, thus forcing the courts to navigate this developing and unclear area of science and make determinations outside their expertise.

Second, because competency requires more than the mere ability to express a preference, Steven does not have the liberty to make this end-of life decision on his own behalf. A patient's ability to make medical decisions with respect to treatment is rooted in the doctrine of informed consent; the doctrine necessarily requires that a patient be able to understand and appreciate the nature and circumstances of his medical condition, as well as manipulate that information rationally to arrive at his decision. Steven's limited cognitive abilities do not meet this standard. Moreover, requiring only a bare expression of a preference risks elevating a patient's unreasoned choice made while incompetent over his previously-expressed decisions made with thoughtful deliberation while competent.

Lastly, New Amsterdam's proxy statute § 294.60 ensures that Steven will not lose his voice in making this end-of-life decision. Under the statute, Michelle will act as Steven's proxy to effectuate his previously-expressed wishes. Her burden is not light: Michelle must support any decision to withdraw life-prolonging medical treatment with trustworthy evidence of Steven's desires, as well as provide evidence that the burden of continuing Steven's life outweighs the benefit.

Accordingly, the Fourteenth Circuit's judgment should be reversed, either because it improperly reversed the District Court's order of abstention, or, alternatively, because it erroneously granted Steven a liberty interest that he lacks.

ARGUMENT

I. THE FEDERAL JUDICIARY SHOULD ABSTAIN FROM THIS MATTER TO AVOID UNDUE INTERFERENCE WITH NEW AMSTERDAM'S LAW AND POLICY.

The Fourteenth Circuit Court of Appeals erred when it reversed the District Court's order of abstention. (R. 15.) This Court reviews whether the requirements for abstention have been met *de novo*. Smelt v County of Orange, 447 F.3d 673, 678 (9th Cir. 2006). If the requirements have been met, this Court reviews the District Court's

decision to abstain for abuse of discretion. Id.

Federal courts have long exercised the authority, under appropriate circumstances, to abstain from exercising jurisdiction properly conferred upon them.¹ This authority stems from a "regard for the respective competence of the state and federal court systems and for the maintenance of harmonious federal-state relations in a matter close to the political interests of a State." La. Power & Light Co. v. City of Thibodaux, 360 U.S. 25, 29 (1959). There is a strong sense that "the National Government will fare best if the States and their institutions are left free to perform their separate functions in their separate ways." Younger, 401 U.S. at 44 (1971). Abstention may be invoked whatever the grounds underlying federal jurisdiction. See Burford v. Sun Oil Co., 319 U.S. 315, 317-318 (1943) (abstention is possible "whether jurisdiction is invoked on the ground of diversity of citizenship or otherwise").

In the instant case, abstention is appropriate based on both the doctrines set forth in <u>Burford</u> and <u>Thibodaux</u>. 319 U.S. at 334; 360 U.S. at 29. Abstention is required under <u>Burford</u> or <u>Thibodaux</u> when timely and adequate state court review is available to the litigants and either: (A) the case presents difficult questions of state law bearing on policies of substantial public importance; or (B) the exercise of federal review will disrupt state efforts to establish a coherent policy with respect to a matter of substantial public concern. *See* <u>New Orleans Pub. Serv., Inc. v. Council of City of New Orleans</u>, 419 U.S. 350, 361 (1989); *see also* <u>Colorado River Conservation Dist. v. U.S.</u>, 424 U.S. 800, 814-815 (1976).

Here, these requirements are met. As a preliminary matter, timely and adequate state court review is available to Respondents because they may still appeal the NASC's decision directly to this Court. Further, exercise of jurisdiction will both require federal resolution of difficult questions of New Amsterdam law regarding end-of-life decision-making, and will disrupt the state's efforts to

¹ Cf., Younger v. Harris, 401 U.S. 37 (1971) (pending state criminal proceeding); R.R. Comm'n of Tex. v. Pullman Co., 312 U.S. 496 (1941) (ambiguous state law and avoidable federal constitutional question); Pennsylvania v. Williams, 294 U.S. 176 (1935) (avoidable duplication of pending state proceeding).

establish coherent policies regarding the same. Thus, abstention is warranted.

A. Abstention is warranted because this case raises difficult questions of state law bearing on policies of substantial importance to the citizens of New Amsterdam.

Abstention is proper where a case presents difficult questions of state law bearing on policy problems of substantial public import whose importance transcends the result in the case then at bar. Colorado River, 424 U.S. at 814 (citing to both <u>Burford</u> and <u>Thibodaux</u> to support the rule). A case thus demands abstention when it: 1) presents matters of state law; 2) requires a federal court to navigate "difficult" questions of that state scheme; and 3) involves issues of substantial public importance to the citizens of the state in question. Here, all three requirements are met; thus, abstention is appropriate.

1. It is the prerogative of the states to craft procedures governing end-of-life decisions for their citizens.

Abstention is favored where a case focuses primarily on questions of state, not federal, law. Burford, 319 U.S. at 319. For example, in Burford, the issue presented to the federal court was whether a state regulatory commission properly applied a specific exception to a state rule governing the drilling of oil in Texas. Id. at 316, 324. In holding that abstention was appropriate, this Court noted that the state had principal regulatory authority over the Texas oil industry, with the federal government only supplementing this authority when necessary. Id. at 319, 332. This Court wished to "give the Texas courts the first opportunity to consider" their own state's regulations, as those courts "alone ha[d] the power to give definite answers to the questions of state law." Id. at 332, 325; see Thibodaux, 360 U.S. at 26, 30 (holding abstention appropriate where the eminent domain issue before the court concerned a power that was a "prerogative of the state" that "may be exercised any way that the state thinks fit"); see also McNeese v. Bd. of Educ. for Cmty. Unit Sch. Dist. 187, Cahokia, Ill., 373 U.S. 668, 674 (1963) (holding abstention

inappropriate where school desegregation claim was purely "federal in origin" and in no way "entangled in a skein of state law that must be untangled before the federal case can proceed").

Here, Respondents ask the federal courts to determine a minimally conscious individual's right and capacity to make end-oflife decisions. (R. 12.) Like the regulation of the oil industry in Burford, 319 U.S. at 319, the regulation of end-of-life decisions, in question here, has long been an area of traditional state authority. See Cruzan v. Dir., Missouri Dept. of Health, 497 U.S. 261, 292 (1990) (O'Connor, J., concurring) (the "challenging task of crafting appropriate procedures" for end-of-life decision-making incompetents "is entrusted to the laboratory of the States.") (internal quotation marks omitted); id. at 293 (Scalia, J., concurring) (stating that rules regarding end-of-life decisions are left "to the citizens of [the states] to decide, through their elected representatives."). To this end, the states have enacted a variety of statutes regulating all aspects of end-of-life decisions, such as the institution of Advance of Directives, the establishment of capacity standards for medical decision-making, and the authorization of surrogate decisionmaking. See, e.g., Health Care Decisions Law, Cal. Prob. Code § 4600-4643 (1999); Illinois Health Care Surrogate Act, 755 Ill. Comp. Stat. 40/1 (1991); New Amsterdam Prob. Code § 294.60.2

Therefore, while Respondents cloak their claim in federal due process language, (R. 12.), it is clear that the real dispute is essentially a matter of state law. As this Court observed in <u>Cruzan</u>, the ultimate "question is not *whether* an incompetent has constitutional rights, but *how* such rights may be exercised." 487 U.S. at 309 (emphasis added). Properly understood, this case is not a matter of whether Steven possesses constitutional rights, but rather how those rights may be exercised within the relevant framework of New Amsterdam state law. Thus, as this case primarily presents questions of state, not federal, law, abstention is favored.

2. A minimally conscious individual's right and capacity to make

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² Notably, the United States Congress has never passed a statute governing these kinds of medical decisions.

end-of-life decisions constitute difficult questions of state law.

This Court has recognized the wisdom in federal courts yielding to state courts where a case presents difficult questions of state law. <u>Burford</u>, 319 U.S. at 318; <u>Thibodaux</u>, 360 U.S. at 27. Questions of state law are difficult when they (a) are highly sensitive to and entangled in local realities and preferences, <u>Burford</u>, 319 U.S. at 319-20, or (b) revolve around an unclear, unsettled state statute. <u>Thibodaux</u>, 360 U.S. at 29. This case presents a difficult question of New Amsterdam state law under both the <u>Burford</u> and <u>Thibodaux</u> abstention doctrines.

a. These questions are difficult under <u>Burford</u> because they are highly sensitive to and entangled in the realities and preferences of New Amsterdam's citizens.

Under <u>Burford</u>, legal issues constitute difficult questions of state law when they are highly sensitive to and entangled in the realities, preferences and laws of the particular state in question. 319 U.S. at 319-320; <u>Koerner v. Garden Dist. Ass'n</u>, 78 F. App'x 960, 963 (5th Cir. 2003) ("In applying <u>Burford</u>. . .the court. . .looks to whether the. . .claim is entangled in an area of law that must be untangled before the federal case can proceed.").

In <u>Burford</u>, this Court was asked to evaluate an order that was part of a general regulatory system devised for the conservation of oil and gas in Texas. 360 U.S. at 331. Describing the problem as "thorny" and "challeng[ing]," this Court found that the regulation of the oil and gas industry was complex and required an intimate knowledge of the local geological conditions in Texas. <u>Id.</u> at 318-319. For example, in regulating the industry, the Texas Commission routinely had to consider how to space the wells, achieve maximum oil extraction, and maintain proper distribution among surface owners. <u>Id.</u> at 323-325. This Court, upholding abstention, observed that "[t]he delusive simplicity with which these principles. . .can be stated should not obscure the actual nonlegal complexities involved in their application. . " <u>Id.</u> at 323.

Here, this Court similarly faces a question elaborately entangled in state law. Like the difficult geological problems accompanying the

regulation of oil in Texas, questions of whether minimally conscious people have the right to make medical decisions on their own behalf implicate non-legal complexities of medical science and local realties. See Cruzan, 497 U.S. at 292 (O'Connor, J., concurring). These determinations necessarily fluctuate between states depending on the particular preferences of their citizens with respect to end-of-life issues - preferences animated by their various cultural, religious, and medical traditions and beliefs. Unique and localized, these preferences must be evaluated before the particular rights of minimally conscious persons can be determined within a specific state. See Id. at 292 (O'Connor, J., concurring) ("no national consensus has yet emerged. . .for this difficult and sensitive problem.").3 Moreover, this Court has dismissed the possibility that it holds the key to answering these difficult questions. Id. at 293 (Scalia, J., concurring) (stating that answers to difficult end-of-life questions are "neither set forth in the Constitution nor known to the nine Justices of this Court").

Abstention is no less proper here merely because this case involves questions of defining competency, rather than questions tethered to local land issues. Questions of state law may be difficult under <u>Burford</u> regardless of the extent to which they involve local land issues. *See* <u>Ankenbrandt v. Richards</u>, 504 U.S. 689, 706 (1992) ("It is not inconceivable. . .that in certain circumstances, the abstention principles developed in <u>Burford v. Sun Oil Co. . .might</u> be relevant in a case involving elements of the domestic relationship. . ."). In <u>Burford</u>, it was not the complexity of the local land issues that justified abstention. 319 U.S. at 327. Indeed, this Court demonstrated a rather firm grasp on the underlying land issues presented. *See* <u>Id.</u> at 318-320. Rather, to be "difficult", a question need only depend on local sensitivities, conditions and realities not readily discernable to the outside eye.

Thus, because Respondents' claim is entangled in complex issues that are sensitive to New Amsterdam's realities and preferences, they

³ Indeed, the scientific community itself has yet to define the precise boundaries of different diagnostic categories across the spectrum of consciousness. Nancy Childs et al., <u>Accuracy of Diagnosis of Persistent Vegetative State</u>, 43(8) Neurology 1465 (1993).

present difficult issues of state law that favor Burford abstention.

b. These questions are also difficult under <u>Thibodaux</u> because the New Amsterdam Supreme Court has never applied its probate laws to minimally conscious individuals.

Under <u>Thibodaux</u>, a legal issue is a difficult question of state law when it revolves around an unsettled, unclear state statute. 360 U.S. at 29. In <u>Thibodaux</u>, a city asserted that a Louisiana statute permitted it to expropriate a tract of land owned by a public utility. <u>Id.</u> at 25. However, the Louisiana Supreme Court had yet to interpret the statute, and the only interpretation was that of the Attorney General who merely speculated as to its application. <u>Id.</u> at 30. Rather than casting a "dubious and tentative forecast," this Court upheld abstention, staying the action pending interpretation by the state supreme court - the "only tribunal empowered to speak definitively" as to the meaning of the statute. <u>Id.</u> at 29.

Here, like the state statute in <u>Thibodaux</u>, New Amsterdam's § 294.60 is unsettled as applied to minimally conscious individuals. The statute mandates surrogate decision-making for "incapacitated or developmentally disabled" individuals. § 294.60(1). Though Steven is incapacitated, the state probate court gave effect to Steven's ambiguous expressions in direct contravention of the statute. (R. 10.) On appeal, the NASC did not review the probate court's erroneous application of the statute. Instead, the NASC gave effect to Steven's Advance Directive, concluding that a MCS was sufficiently similar to a PVS. (R. 11.) In so holding, the NASC left unsettled the application of § 294.60 to minimally conscious patients. (R. 11.)

Moreover, the NASC's dicta seem to confound, rather than clarify, the statutory scheme. The court observed that Tyler and Florence Keller did not satisfy the evidentiary burden imposed upon them by § 294.60 to provide evidence that Steven wished to continue receiving treatment in his MCS. (R. 11.) However, the statute explicitly places the burden of proof upon the proponents of withdrawing treatment, and is silent as to any possible burden placed on those who seek to maintain the status quo. § 294.60(3) ("A proxy's decision to withhold or withdraw life-prolonging procedures must be supported by trustworthy evidence") (emphasis added).

Because the NASC has yet to resolve the statute's applicability to MCS patients and its evidentiary burden, any ruling by a federal court will only amount to a "forecast" of any future interpretation rendered by the NASC. The statute is unclear and un-interpreted; this Court is therefore presented with a "difficult" question of state law that justifies abstention under <u>Thibodaux</u>.

3. The resolution of this end-of-life issue is of substantial public importance because it will affect the entire New Amsterdam regulatory system to which all citizens of the state are subject.

A matter is of substantial public importance when it is poised to affect an expansive state system that has direct consequences for many citizens of that state. Burford, 319 U.S. at 323-324. In Burford, this Court declined to render judgment on the statutory exception at issue partially because "[t]he sheer quantity of exception cases ma[de] their disposition of great public importance." Id. Well-aware of the "volume of litigation" that would potentially ensue, this Court did not want to render judgment that would ultimately influence the "entire state conservation system." Id. at 324 (emphasis added). Not only would a ruling go to the "heart" of Texas' "control program," but the significance of the potential judgment would transcend the immediate dispute. Id. at 328. Specifically, this Court observed that "[o]f far more importance than any. . .private interest is the fact that the over-all plan of regulation, as well as each of its case by case manifestations, is of vital interest to the general public." Id. at 24. Thus, this Court upheld abstention in light of the overwhelming effect a ruling would have on a vast regulatory system in Texas upon which many citizens of the state relied.

In the instant case, the issues presented are likewise of substantial importance to the citizens of New Amsterdam. First, the "sheer quantity" of potential end-of-life decisions made on the basis of a possible ruling here renders this issue one of great public concern. As the American Hospitals Association has noted, "thousands of decisions to forego life-sustaining medical treatment are made" everyday. (American Hospitals Association Br. 2, 1989 WL 1115252 (U.S. Sep. 01, 1989)). A ruling by this Court will reverberate throughout the entire New Amsterdam system for handling end-of-

life decision-making, a system in which New Amsterdam citizens necessarily have a "vital interest." See <u>Burford</u>, 319 U.S. at 324. Second, the speed with which the New Amsterdam legislature initiated legislation in response to the NASC's ruling further demonstrates the significance of this matter. (R. 11.) Finally, the media frenzy over Steven, coupled with the public's overwhelming interest in his case,⁴ are additional indicia of this issue's substantial public importance. (R. 11.)

This issue, then, is not a discrete question pertaining to the isolated parties before this Court. Rather, it is transcendent: every citizen of the state may potentially be in a MCS, have a family member in a MCS, or be called upon to make proxy decisions. The exercise of jurisdiction will therefore require this Court to announce a rule of substantial importance to New Amsterdam citizens regarding an issue on which, thus far, only their elected representatives have spoken.

In sum, the questions of end-of-life decision-making presented by this case are: (1) issues of state law; (2) "difficult" under both <u>Burford</u> and <u>Thibodaux</u>, respectively, because they are highly sensitive to and entangled in New Amsterdam's state laws and preferences, and revolve around the as-yet unsettled § 294.60; and (3) of substantial public importance to New Amsterdam's citizens. As the three requirements under this first test are met, abstention is warranted.

B. Abstention is also warranted because the exercise of federal review will disrupt New Amsterdam's ongoing efforts to establish a coherent framework for addressing end-of-life decision-making.

Abstention is also proper under <u>Burford</u> "where the exercise of federal review of the question in [the] case would be disruptive of state efforts to establish a coherent policy with respect to a matter of substantial public concern." <u>New Orleans Pub. Serv., Inc.</u>, 419 U.S. at

⁴ The videotape of Steven has been viewed over 5,000,000 times on www.youtube.com. (R. 11.)

361. A matter may be disruptive where a state's regulatory scheme on a given issue is unified and complex, and contemplates a particular course of state review. <u>Burford</u>, 319 U.S. at 325-327.

For example, in <u>Burford</u>, the Texas legislature created the Texas Railroad Commission, giving it great discretion to apply Texas policy to the regulation of oil. <u>Id.</u> at 325. The legislature checked the Commission's oversight by providing a thorough system of state-court judicial review, which guaranteed that problems with the regulation of oil would be resolved by those with the "specialized knowledge" necessary to "shap[e] the policy of regulation of the ever-changing demands in this field." <u>Id.</u> at 327. This complex system of regulation and review, in part, prompted this Court to defer to Texas courts on matters of oil regulation. <u>Id.</u>; *see also* <u>Ala. Pub. Serv. Co. v. S. Ry. Co.</u>, 341 U.S. 341, 349 (1951) (stating that <u>Burford</u> abstention is appropriate where there is in place an adequate system for local, fact-specific review that is appealable.)

Similar to the complex scheme in Burford, New Amsterdam has a highly developed and unified system for addressing end-of-life decision-making. See § 294.60. Like Texas' scheme, Amsterdam's begins outside the judicial system. Almost without exception, the determination of a patient's capacity to make a medical decision is made by that patient's doctors, in accordance with institutional advisory mechanisms, such as ethics committees. (R. 6.) These doctors, intimately familiar with the patients under their care, possess specialized knowledge in making capacity determinations; when a patient is deemed capable, his decisions are effectuated. (R. 6-7.)

If incapacitated, a patient's course of treatment is governed by § 294.60. The statute prioritizes surrogates, sets the evidentiary burden for withdrawal of treatment, and gives institutional and community-based ethics committees, preapproved by the New Amsterdam Bioethics Network, supplemental decision-making authority. §§ 294.60(1)-(3). Just as a particular court was designated to review the Railroad Commission's orders in <u>Burford</u>, 319 U.S. at 327, New Amsterdam's Probate Courts are likewise designated to review the extra-judiciary decisions of hospitals, surrogates, and ethics committees. These courts have the authority to review patients'

capacity and whether the statutory evidentiary burdens have been satisfied. See (R. 9-10.)

The Steven Keller Act, already passed by the New Amsterdam legislature and awaiting the Governor's signature, will add further comprehensiveness and complexity to New Amsterdam's scheme. See (R. 11-12.) The Act sets forth an evidentiary rubric governing end-of-life decisions for minimally conscious individuals. See (R. 11-12.) The rubric provides for careful patient-evaluation by a panel of doctors, more nuanced standards for determining capacity, and heightened evidentiary burdens for surrogate decision-making. See (R. 11-12.)

Both the existing statutory framework and the ongoing attempts to modify the scheme constitute a coherent, complex and unified framework for regulating end-of-life decision-making for minimally conscious persons. Federal review of the question presented will disrupt New Amsterdam's existing and developing framework for addressing these issues. Further, the New Amsterdam legislature is in the midst of devising a framework specifically geared towards individuals like Steven. *See* (R. 11-12.) Federal review thus risks the substitution of the judiciary's preferences for those of the elected representatives of New Amsterdam on a matter traditionally left to the states. Therefore, under this second test, abstention is warranted due to the possibility that federal review will disrupt New Amsterdam's efforts to establish a coherent framework for these issues.

In conclusion, abstention is warranted under either the first or second test because this case presents difficult questions of New Amsterdam law of substantial importance to its citizens, and because federal review risks disrupting New Amsterdam's ongoing efforts to establish a coherent framework for addressing end-of-life decisions. With abstention requirements satisfied, and nothing indicating an abuse of discretion on the part of the District Court, the Fourteenth Circuit erred in reversing the District Court's order of abstention.

II. WHILE IN A MINIMALLY CONSCIOUS STATE, STEVEN KELLER DOES NOT HAVE A LIBERTY INTEREST UNDER THE DUE PROCESS CLAUSE IN DETERMINING

WHETHER TO CONTINUE LIFE-PROLONGING MEDICAL TREATMENT.

Even if the Fourteenth Circuit properly declined to abstain from this matter, Steven nevertheless does not have a liberty interest in determining on his own behalf whether to continue life-prolonging medical treatment. Respondents' claim relies upon the language of the Fourteenth Amendment, guaranteeing that no person shall be deprived of life, liberty or property without due process of law. U.S. Const. Amend. XIV., § 1. This Court reviews due process cases *de novo*. Bose Corp. v. Consumers Union of U.S., Inc., 466 U.S. 485, 486 (1984).

Advancements in life-prolonging medical technologies have "effectively created a twilight zone of suspended animation where death commences while life, in some form, continues." Rasmussen v. Fleming, 741 P.2d 674, 678 (Ariz. 1987) (en banc). Steven Keller currently resides in that twilight zone, completely reliant on artificial hydration and nutrition. Now, Respondents seek to replace Steven's previously-expressed wishes that he be permitted to die with dignity, made while competent, with expressions Steven made while minimally conscious. (R. 7-8.) They assert that the Fourteenth Amendment requires that his expressions made while minimally conscious be given effect. (R. 12.) It does not.

This Court should reverse the Fourteenth Circuit Court of Appeals on this issue for the following reasons: First, Steven does not possess a liberty interest in making medical decisions on his own behalf merely because he is minimally conscious, rather than in a PVS or coma. Second, Steven lacks the required competency to possess this liberty interest. Finally, the denial of this liberty interest does not deprive Steven of his voice in this decision; allowing Michelle to exercise her surrogate authority best preserves Steven's previously-expressed wishes made while competent.

A. Steven must be competent to possess this liberty interest, not merely conscious.

Competency, not consciousness, is the touchstone for possessing a liberty interest in determining whether to withdraw life-prolonging treatment. See Conservatorship of Wendland, 28 P.3d 151, 158 (Cal. 2001); see also Keller v. Keller, No. 09-1173, at *24, (14th Cir. Oct. 1, 2009) (Chiarello, J., dissenting) ("the threshold issue . . . is whether a minimally conscious person is competent"). This Court's annunciation of the well-accepted competency standard in Cruzan, 497 U.S. at 278, coupled with the difficulties in abandoning the standard for an alternative based on consciousness, makes clear that to possess this liberty interest, an individual must be competent, not merely conscious.

1. The competency standard is well-settled, applying to all patients irrespective of their degrees of consciousness.

A competent person has a constitutionally protected liberty interest in deciding whether to withdraw life-prolonging treatment. Cruzan, 497 U.S. at 278 ("The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.") Further, while incompetent individuals hypothetically have this same interest, it must necessarily be exercised for them by competent individuals. Id. at 279 (upholding a surrogate decision while rejecting the claim that "an incompetent person should possess the same right in this respect as is possessed by a competent person"); see Tarlow v. District of Columbia, 489 F.3d 376, 382 (D.C. Cir. 2007) ("accepting the wishes of patients who lack. . .the mental capacity to make medical decisions does not make logical sense").

Courts have not deviated from this competency standard when dealing with conscious persons. For example, in <u>Conservatorship of Wendland</u>, the Supreme Court of California dealt with whether artificial nutrition and hydration could be withheld from a minimally conscious, but otherwise incompetent, individual named Robert. 28 P.3d at 167. Robert's functioning allowed him to throw and catch a ball, turn pages, and, at times, communicate via a yes/no board. <u>Id.</u> at 154-155. However, his treating physician concluded that, to the highest degree of medical certainty, Robert was unable to make medical treatment decisions for himself. <u>Id.</u>

In navigating the question of treatment withdrawal, the court did not attach any significance to Robert's consciousness. *See* <u>Id.</u> at 158.

Instead, it proceeded in the usual analysis grounded in Robert's incompetence. <u>Id.</u> Though the court ultimately held that Robert's conservator did not meet her evidentiary burden to justify withdrawing treatment, it never hesitated in using competency, rather than consciousness, as a guidepost for determining Robert's rights. <u>Id.</u> at 167-168; *accord* <u>In Re Martin</u>, 538 N.W.2d 399, 401-402 (Mich. 1995).

Here, like the incompetent patient in <u>Wendland</u>, Steven is minimally conscious and exhibits limited cognitive functioning, only demonstrating a limited ability to communicate in a yes-or-no fashion. 28 P.3d at 155 n.5; (R. 6). Respondents now ask this Court to grant Steven a liberty interest in deciding whether to withdraw medical treatment. (R. 12.) If they assert this right on the mere basis of Steven's consciousness, this Court should, like the Supreme Courts of California and Michigan, question the extent to which Steven is competent, and decline to give dispositive effect to the mere fact of his minimal consciousness. Competency, not consciousness, is the standard for determining whether a patient possesses a liberty interest in deciding to withdraw life-prolonging treatment.

2. An alternative standard based on consciousness would result in a flood of litigation asking courts to employ highly scientific strategies for identifying where individuals fall on the continuum of consciousness.

A liberty interest based on consciousness, rather than competence, would effectively reduce many end-of-life cases to disputes over science. Instead of hearing questions on whether a given patient is legally competent to make a medical decision, courts would likely be flooded with questions of whether, medically, a patient is in fact minimally conscious. Not only are courts inadequately equipped to decide such questions, but medical science itself has yet to delineate the boundaries of consciousness.

The diagnosis of a MCS is not clearly defined. Joseph Giancino & Kathleen Kalmar, The Vegetative and Minimally Conscious States: A Comparison of Clinical Features and Functional Outcome: Journal of Head Trauma Rehabilitation, 12(4) J. Head Trauma Rehab. 36 (1997). When the MCS was first recognized in 1997, researchers set forth a

list of behaviors that evinced the consciousness necessary for a MCS, rather than PVS, diagnosis. Id. Steven was presumably diagnosed under these same criteria – which were, admittedly, arbitrarily chosen. The Aspen Neurobehavioral Conference Work Group, Assessment, Prognosis and Treatment of the Vegetative and Minimally Conscious States: The Aspen Neurobehavioral Conference Consensus Statement 12-13 (1999).

The arbitrariness of these criteria is inevitable, given that the line between a MCS and a PVS is, at best, blurry and, at worst, nonexistent. Lawrence J. Nelson & Ronald E. Cranford, Michael Martin and Robert Wendland: Beyond the Vegetative State, 15 J. Contemp. Health L. & Pol'y 427, 429 (1999). In fact, the MCS and PVS "may actually represent points along the same continuum of consciousness." Aspen Consensus Statement at 12-13. Yet, even given these diagnostic criteria, doctors still experience difficulty in accurately applying the criteria to severely brain-damaged patients. Caroline Schnakers et al., Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standard Neurobehavioral Assessment, 9(35) BMC Neurology 1 (2009). Studies demonstrate that doctors consistently fail in their ability to properly diagnose the MCS. Id. (referencing a study showing that approximately forty percent of those patients diagnosed in a PVS are actually in a MCS).

Despite these problems, Respondents now urge this court to define an unworkable liberty interest based on a diagnosis that the patient is in MCS. Just as the criteria for identifying a MCS patient were arbitrarily chosen, a liberty interest based on these same criteria would be equally tenuous. Moreover, if in fact consciousness is a sliding scale, then this new liberty interest would continually need redefinition as science and technology progress and the ability to penetrate the human brain improves. Finally, this liberty interest would force courts to do what doctors themselves cannot do with accuracy – diagnose a patient as being in a MCS. Unlike determining legal competency, which courts are clearly competent to do, determining consciousness would force courts to delve into this developing and unclear area of science to make determinations outside their expertise.

B. Given Steven's substantially diminished cognitive abilities, Steven is not competent to make medical decisions.

Steven does not possess a liberty interest in determining, on his own behalf, whether to withdraw life-prolonging medical treatment because his limited cognitive functioning renders him incompetent to make medical decisions. This Court recognizes no distinction between end-of-life decisions and other medical decisions. *See* Cruzan, 497 U.S. at 306 ("The rule [regarding medical self-determination] has never been qualified in its application by either the nature or purpose of the treatment, or the gravity of the consequences of acceding to or foregoing it."). The ability to make medical decisions is grounded in the informed consent doctrine. <u>Id.</u> at 277.

The doctrine of informed consent states that consent for a medical procedure is only valid if it is given by a competent person after that person has received a "fair and reasonable explanation of the contemplated treatment or procedure." Sard v. Hardy, 379 A.2d 1014, 1019 (Md. 1977). This standard promotes patients' autonomous decision-making; embedded in this autonomy are "concrete requirements of capacity." Jessica W. Berg, et al., Constructing Competence: Formulating Standards of Legal Competence to Make Medical Decisions, 48 Rutgers L. Rev. 345, 346 (1996). While judicial opinions dealing with this issue generally do not explicitly articulate tests for competency, the doctrine of informed consent supports an expanded, rather than bare-minimum, formulation.

For a patient to be competent to make medical decisions he must, in addition to expressing a treatment preference, be able to understand and appreciate the nature of his medical circumstances and condition, and to engage in rational decision-making. Paul S. Appelbaum & Thomas Grisso, <u>Assessing Patients' Capacity to Consent to Treatment</u>, 319 New Eng. J. Med. 1635, 1635-38 (1988). In other words, even assuming *arguendo* that Steven can respond accurately to objective questions,⁵ that is not enough. The

⁵ A clinical feature of the minimally conscious state is "gestural or verbal 'yes/no' responses (regardless of accuracy)." Nelson & Cranford, supra, at 428 (emphasis added).

competency standard, inseparable from the principles of informed consent, plainly requires something more than the bare ability to express a choice.

1. To qualify as competent, a patient must understand and appreciate the nature and circumstances of his medical condition.

To be competent to make a medical decision, a person must be able to understand and appreciate his medical condition and the consequences of his decision. See Grannum v. Berard, 422 P.2d 812, 815 (Wash. 1967) (stating that a patient is not competent to consent to a medical procedure where he cannot "comprehend[] the nature, terms and effect of consent"); In re Farrell, 529 A.2d 404, 413 n.7 (N.J. (stating that a competent patient understands characteristics of his illness, his prognosis, and the benefits and risks of a treatment option). Understanding requires a base ability "to comprehend the concepts involved" in a decision. Berg, supra, at 353-Appreciation requires a further ability to apply understanding to his situation, that is, to "acknowledge[] his or her illness and the potential value of treatment." Id. at 355, 366.

Understanding and appreciation are necessary to give full effect to a person's autonomy by allowing him to make *meaningful* choices about their treatment. Where either is lacking, courts run the risk of giving effect to a decision made with neither complete information, nor the ability to assess that information. *See* Thomas J. Marzen and Daniel Avila, Will the Real Michael Martin Please Speak Up! Medical Decisionmaking for Questionably Competent Persons, 72 U. Det. Mercy L. Rev. 833, 844 (1995). This undermines both the concepts of individual autonomy and informed consent. Berg, supra, at 377.

For example, in <u>In re Roe</u>, 583 N.E.2d 1282, 1288 (Mass. 1992), the Massachusetts Supreme Court held that a patient was incompetent and thus unable to refuse antipsychotic drugs because he could not understand or appreciate his medical condition. There, the patient was diagnosed as a schizophrenic, yet refused to admit that he was mentally ill. <u>Id.</u> at 1288. Due to this inability to understand his medical condition, the court held that he was unable to make a meaningful decision regarding his treatment – he could not

"appreciate the need to control his illness" nor understand "the risks of refusing" treatment. <u>Id.</u> at 1286.

Conversely, in Lane v. Candura, 376 N.E.2d 1232, 1236 (Mass. App. Ct. 1978), a woman was allowed to refuse to have her gangrenous leg amputated. The court held that she was competent to make that decision because she understood the nature and consequences of her decision, and was thus able to make a meaningful decision. Id. In both of these cases, the court sought to give effect only to competent decisions – those decisions made with understanding and appreciation of the nature and circumstances of the patient's medical condition. These elements are indispensable from any competency standard that seeks to uphold principles of patient autonomy.

2. The competency standard further requires that a patient be able to engage in rational decision-making.

To qualify as competent, a patient must be able to undergo rational decision-making processes. *See* <u>Cruzan</u>, 497 U.S. at 309. This requires the patient to "employ logical thought processes to compare the risks and benefits of treatment options." Berg, <u>supra</u>, at 357. This Court implicitly adopted this rationality requirement in <u>Cruzan</u>. 497 U.S. at 309. It recognized that the line between competency and incompetency is whether one's "status renders [him] unable to exercise choice freely and rationally." <u>Id.</u>

The lower courts have similarly adopted this rationality requirement in their standards for competency. For example, in <u>United States v. Charters</u>, 829 F.2d 479, 496-497 (4th Cir. 1987), the Fourth Circuit held that to determine whether an individual is competent to make medical decisions, courts must "evaluate whether a [patient] follow[s] a rational process in deciding to refuse [treatment] and can give rational reasons for the choice he has made." *See also <u>United States v. Waddell</u>*, 687 F.Supp. 208, 209 (M.D.N.C. 1988) ("to determine [patient's] competence, the court should evaluate whether [he] has followed a *rational process* in deciding whether to reject [treatment] and whether he can give *rational reasons* for [his] choice") (emphasis added).

This rationality requirement must not be confused with a

competency standard that demands a "reasonable result" or concerns the conventionality of a patient's decision. Indeed, to require a reasonable outcome risks barring "the expression of idiosyncratic preferences." Elyn R. Saks, <u>Competency to Refuse Treatment</u>, 69 N.C. L. Rev. 945, 952 (1991). A requirement that people live according to some objective standard—according to "someone else's conception of the good" – completely frustrates the competency doctrine. <u>Id.</u>

The rationality requirement, though, does not go so far. It simply requires that a patient, with an understanding of his condition, be able to manipulate information with rationality to arrive at a medical decision – however reasonable that decision may be. This test therefore avoids paternalistic threats to a patient's right to make choices which reflect his unique concerns. See Charters, 829 F.2d at 496-407 ("[l]atitude must be given in defining a 'rational reason'"). As long as a patient can demonstrate that the final decision flows from certain reasons, the rationality requirement is satisfied. See Berg, supra, at 359 n.49 (citing to Benjamin Freedman, Competence, Marginal and Otherwise, 4 Int'l J.L. & Psychiatry 53 (1981) (noting that a "rational reasons" test should focus on the process of decisionmaking, not the end result) (emphasis added)). Competency must thus include a requirement of rationality to ensure meaningful decision-making.

Here, it does not appear that Steven satisfies this competency standard. The record does not support the inference that Steven is able to understand, appreciate or rationally contemplate his medical situation. Indeed, Steven's abilities are limited to reflexes, occasionally following simple commands, and rarely and unpredictably nodding or shaking his head when asked simple yesor-no questions. (R. 6.) Such minimal abilities do not evince the required functioning for informed decision-making.

3. A competency standard that is satisfied upon a mere showing of Steven's ability to express a choice risks inaccurately effectuating his wishes.

If the competency standard were satisfied simply upon a showing that a patient can express a preference, regardless of that patient's understanding, appreciation and rationality, the underlying notions of informed consent would be compromised. *See* Berg, <u>supra</u>, at 353. Such a standard "fails to afford adequate care and protection" to the patient, <u>Charters</u>, 829 F.2d at 496 n.26, and would "allow a number of patients with poor decisionmaking capacity to make decisions." Berg, <u>supra</u>, at 353. This standard has the dangerous potential to undermine true patient autonomy. Accordingly, this Court should reject this minimum standard for competency.

Adopting a mere preference-based standard for end-of-life decision-making, as Respondents urge, may lead to anomalous results that undermine a patient's true desires. For example, in In re O'Brien, 517 N.Y.S.2d 346, 346-347 (N.Y. Sup. Ct. 1986), a New York appellate court dealt with whether a feeding tube should be removed from an incompetent but conscious 83-year-old Catholic priest. The priest attempted to remove his feeding tube 15 times, and four examining psychiatrists concluded he was competent to make this decision to withdraw life-prolonging medical treatment. Id. at 347. The court, however, concluded otherwise, reasoning that though the priest was capable of "reacting to his basic needs and wants, and perfectly capable of expressing his irritation . . . he [was] not competent to make the profound decisions about medical treatment, the prolongation of life and the theological implications which would follow from a removal of the feeding tube on demand." Id. at 348.

Had the appellate court accepted a preference-based competency standard, the Catholic priest would have been permitted to authorize the removal of his feeding tube, despite his religious convictions to the contrary. <u>Id.</u> This "choice," devoid of the safeguards of informed consent, would have stripped the priest of his autonomy by exalting uninformed expressions made when minimally conscious over a rational and deliberate choice made when competent. Moreover, this case exposes the frailty of Respondents' argument that their propounded standard necessarily errs on the side of preserving life.

Here, this preference-based standard risks similarly subverting Steven's wishes expressed when competent. Steven clearly indicated, both in his Advance Directive and in informal conversation with peers, that he never wanted to live in complete dependence on medical technologies. These wishes are now under attack simply because Steven gestured in response to an ambiguous question regarding his medical treatment. The competency standard, though, requires something more than a mere ability to express preferences. Patients must be able to understand and appreciate the nature of their circumstances and demonstrate the ability to engage in rational thought. A lesser standard risks inaccurately effectuating Steven's wishes.

C. Steven's wishes are nevertheless safeguarded through New Amsterdam's heightened evidentiary requirements for proxy decision-making.

Denying Steven this liberty interest by no means deprives him of participating in this decision. Because an incompetent person cannot exercise the right to refuse treatment, "[s]uch a 'right' must be exercised for [him]. . .by some sort of surrogate." <u>Cruzan</u>, 497 U.S. at 280. Indeed, such surrogate decision-making "may well be constitutionally required to protect the patient's liberty interest." <u>Id.</u> at 289 (O'Conner, J., concurring).

Empowering a surrogate decision-maker alleviates the risk that a patient's decisions made while competent will be overridden by unreasoned and irregular responses to ambiguous questions. Denying a surrogate decision-maker the ability to effectuate those wishes expressed when competent not only does a disservice to the patient's previous rational decision, but also runs directly counter to the doctrine of informed consent.

New Amsterdam's proxy statute secures these principles by imposing evidentiary requirements as prerequisites for proxy decision-making. § 294.60(3). The statute states that when an "incapacitated or developmentally disabled patient has not executed an advance directive, [or] designated a surrogate" the patient's spouse, above all others, is authorized to make decisions on behalf of the patient. Id. § (1). Decisions made by the proxy must be based on what the patient would have done under the circumstances, or, if no indication of that decision exists, then based on the best interests of the patient. Id. § (2). To ensure that any decision to withdraw life-prolonging procedures is not made with haste or bad faith, such decisions must not only be supported by trustworthy evidence, but also corroborated with evidence that the burden of continuing the

patient's life is greater than the benefit of life to that patient. <u>Id.</u> § (3).

Thus, the statute's safeguards guarantee that Steven will not lose his voice merely because he is incompetent. Indeed, Petitioners wish to give effect to Steven's previously expressed, constitutionally protected wishes, made while competent. While Respondents believe that Steven, in a MCS, can indicate his preference, Steven's present behavior does not reflect a true exercise of his autonomy because his present condition conflicts with his true self-identity. Decisions made by Steven "when he could bring to bear all his faculties" should be preferred as "authentic expressions of his fully autonomous self, over conflicting expressions made when he was not fully autonomous." Marzen & Avila, <a href="suppraction-up-nation-to-up-nation-up-n

CONCLUSION

For all the reasons stated above, the judgment of the United States Court of Appeals for the Fourteenth Circuit should be reversed.

APPENDIX "A"

NEW AMSTERDAM DIRECTIVE TO PHYSICIANS AND FAMILY OR SURROGATES

Instructions for completing this document:

This is an important legal document known as an Advance Directive. It is designed to help you communicate your wishes about medical treatment at some time in the future when you are unable to make your wishes known because of illness or injury. These wishes are usually based on personal values. In particular, you may want to consider what burdens or hardships of treatment you would be

willing to accept for a particular amount of benefit obtained if you were seriously ill.

You are encouraged to discuss your values and wishes with your family or chosen spokesperson, as well as your physician. Your physician, other health care provider, or medical institution may provide you with various resources to assist you in completing your advance directive. Brief definitions are listed below and may aid you in your discussions and advance planning. Initial the treatment choices that best reflect your personal preferences. Provide a copy of your directive to your physician, usual hospital, and family or spokesperson. Consider a periodic review of this document. By periodic review, you can best assure that the directive reflects your preferences.

DIRECTIVE

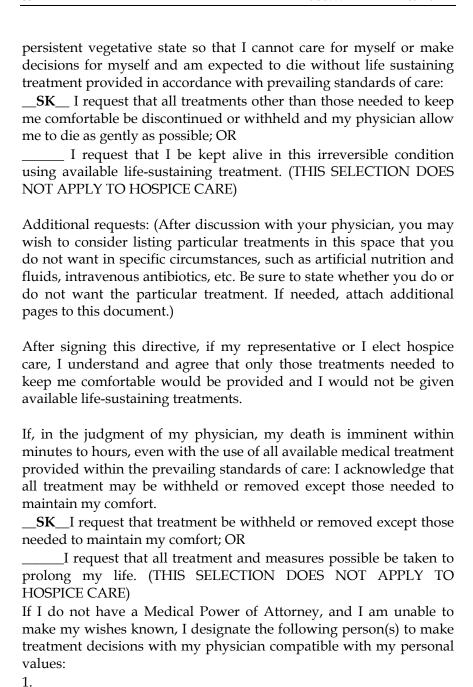
I, Steven Keller, recognize that the best health care is based upon a partnership of trust and communication with my physician. My physician and I will make health care decisions together as long as I am of sound mind and able to make my wishes known. If there comes a time that I am unable to make medical decisions about myself because of illness or injury, I direct that the following treatment preferences be honored:

If, in the judgment of my physician, I am suffering with a terminal condition from which I am expected to die within six (6) months, even with available life-sustaining treatment provided in accordance with prevailing standards of medical care:

__SK__ I request that all treatments other than those needed to keep me comfortable be discontinued or withheld and my physician allows me to die as gently as possible; OR

_____ I request that I be kept alive in this terminal condition using available life-sustaining treatment. (THIS SELECTION DOES NOT APPLY TO HOSPICE CARE)

If, in the judgment of my physician, I am suffering in a coma or



2.

(If a Medical Power-of-Attorney has been executed, then an agent has already been named and you should not list additional names in this document.)

If the above persons are not available, or if I have not designated a spokesperson, I understand that a spokesperson will be chosen for me following standards specified in the laws of New Amsterdam. I understand that under New Amsterdam law, this directive has no effect if I have been diagnosed as pregnant. This directive will remain in effect until I revoke it. No other person may do so.

Declarant (Print Name): Steven Keller

Signature: /s/ Steven Keller Date: September 15, 2000

City, State of Residence: New Amsterdam City, New Amsterdam

Two competent adult witnesses must sign below, acknowledging the signature of the declarant. The witness designated as Witness 1 may not be a person designated to make a treatment decision for the declarant and may not be related to the declarant by blood or marriage. This witness may not be entitled to any part of the estate and may not have a claim against the estate of the declarant. This witness may not be the attending physician or an employee of the attending physician. If this witness is an employee of a health care facility in which the declarant is being cared for, this witness may not be involved in providing direct patient care to the declarant. This witness may not be an officer, director, partner, or business office employee of a health care facility in which the declarant is being cared for or of any parent organization of the health care facility.

Witness 1 (Print Name): Bryan Jennings Witness 1 (Signature): /s/ Bryan Jennings Witness 2 (Print Name): Joseph Jones Witness 2 (Signature): /s/ Joseph Jones

DEFINITIONS

"Artificial nutrition and hydration" means the provision of nutrients or fluids by a tube inserted in a vein, under the skin in the

subcutaneous tissues, or in the stomach (gastrointestinal tract).

"Coma" means that the patient;

- 1. Has entered a state of unconsciousness from which he/she cannot be awakened;
- 2. Has minimal or no response to stimuli; and
- 3. Does not initiate voluntary activity/activities.

"Life-sustaining treatment" means treatment that, based on reasonable medical judgment, sustains the life of a patient and without which the patient will die. The term includes both life-sustaining medications and artificial life support such as mechanical breathing machines, kidney dialysis treatment, and artificial hydration and nutrition. The term does not include the administration of pain management medication, the performance of a medical procedure necessary to provide comfort care, or any other medical care provided to alleviate a patient's pain.

"Terminal condition" means an incurable condition caused by injury, disease, or illness that according to reasonable medical judgment will produce death within six (6) months, even with available lifesustaining treatment provided in accordance with the prevailing standard of medical care.

"Persistent vegetative state" means that the patient;

- 1. Demonstrates some arousal and general responses to pain; and
- 2. Has sleep-wake cycles, respiratory functions and digestive functions; *but*
- 3. Does not have the ability to interact with his/her environment.

APPENDIX "B"

VIDEO TRANSCRIPT

Florence: Steven, do you know who I am?

Steven: (pause) Nods

Florence: So you know I'm your momma?

Steven: Nods

Florence: Your poppa's here too. We love you.

Tyler: Son, is there anything we can do for you?

Steven: (pause) Shakes head

Tyler: Son, the doctors say that you're not going to get much better. But once you can go home, Momma and I want to take you home with us. It'd be easier on Maddie & little Stevie. They can come, too, or come visit you. Whatever they want; we love them too. Before that can happen, though, there's something really important we need to know. Son, they want to stop your feeding tube and let you starve to death. Wouldn't you rather come home with us or do you want to die?

Steven: (pause) Shakes head

Florence: I knew it, Poppa. (Cries)

(Tape ends)

APPENDIX "C"

New Amsterdam Probate Code § 294.60

The Proxy

(1) If an incapacitated or developmentally disabled patient has not executed an advance directive, or designated a surrogate to execute an advance directive, or the designated or alternate surrogate is no longer available to make health care decisions, health care decisions may be made for the patient by any of the following individuals, in the following order of priority, if no individual in a prior class is reasonably available, willing, or competent to act:

- (a) The judicially appointed guardian of the patient or the guardian advocate of the person having a developmental disability, who has been authorized to consent to medical treatment, if such guardian has previously been appointed; however, this paragraph shall not be construed to require such appointment before a treatment decision can be made under this subsection;
- (b) The patient's spouse;
- (c) An adult child of the patient, or if the patient has more than one adult child, a majority of the adult children who are reasonably available for consultation;
- (d) A parent of the patient;
- (e) The adult sibling of the patient or, if the patient has more than one sibling, a majority of the adult siblings who are reasonably available for consultation;
- (f) An adult relative of the patient who has exhibited special care and concern for the patient and who has maintained regular contact with the patient and who is familiar with the patient's activities, health, and religious or moral beliefs; or
- (g) A close friend of the patient.
- (h) A clinical social worker licensed pursuant to chapter 462, or who is a graduate of a court approved guardianship program. Such a proxy must be selected by the provider's bioethics committee and must not be employed by the provider. If the provider does not have a bioethics committee, then such a proxy may be chosen through an arrangement with the bioethics committee of another provider. The

proxy will be notified that, upon request, the provider shall make available a second physician, not involved in the patient's care to assist the proxy in evaluating treatment. Decisions to withhold or withdraw life-prolonging procedures will be reviewed by the facility's bioethics committee. Documentation of efforts to locate proxies from prior classes must be recorded in the patient record.

- (2) Any health care decision made under this part must be based on the proxy's informed consent and on the decision the proxy reasonably believes the patient would have made under the circumstances. If there is no indication of what the patient would have chosen, the proxy mayconsider the patient's best interest in deciding that proposed treatments are to be withheld or that treatments currently in effect are to be withdrawn.
- (3) A a proxy's decision to withhold or withdraw life-prolonging procedures must be supported by trustworthy evidence of what the patient would have chosen had he been competent, and evidence that the burden of the patient's continued life with treatment outweighs the benefit of life for that patient. If there is no indication of what the patient would have chosen, the hospital's medical ethics committee of the facility where the patient is located should consult with the patient's guardian and attending physician(s) to determine whether the decision to withhold or withdraw life-prolong procedures is in the patient's best interest. If there is no medical ethics committee at the facility, the facility must have an arrangement with the medical ethics committee of another facility of another facility or with a community-based ethics committee approved by the New Amsterdam Bio-ethics Network.