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| | ] | SUPERIOR COURT |
| Plaintiff | ] | OF NEW JERSEY |
| Jacqueline Betancourt, | ] | APPELLATE DIVISION |
| On Behalf of | ] | **Docket No. A-3849-08T2** |
| Ruben Betancourt, | ] | |
| | ] | |
| vs. | ] | CIVIL ACTION |
| | ] | |
| | ] | On Appeal from a Final |
| Defendant | ] | Decision of the Superior |
| Trinitas Hospital | ] | Court of New Jersey, |
| | ] | Chancery Division, |
| | ] | Docket No. UNN-C-12-09 |
| | ] | Sat Below: |
| | ] | Hon. John F. Malone, J.S.C. |

# BRIEF OF AMICI CURIAE, NOT DEAD YET, ADAPT, CENTER FOR SELF-DETERMINATION, NATIONAL COUNCIL ON INDEPENDENT LIVING, NATIONAL SPINAL CORD INJURY ASSOCIATION, AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES, and DISABILITY RIGHTS NEW JERSEY

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TABLE OF CONTENTS

TABLE OF CONTENTS . . . . . i.

TABLE OF AUTHORITIES . . . . . v.

INTRODUCTION . . . . . 1.

POSITION OF AMICI CURIAE NOT DEAD YET, ET AL. . . . . 2.

PROCEDURAL HISTORY . . . . . 5.

STATEMENT OF FACTS . . . . . 7.

ARGUMENT . . . . . 16.

I. The Appellants' motion to dismiss the case as moot should be granted. . . . . 17.

II. The Court was correct to determine that Mr. Betancourt is an incapacitated person, and to appoint Jacqueline Betancourt as her father's guardian. . 20.

A. The court's findings of fact that Mr. Betancourt is incapacitated and that Jacqueline Betancourt is an appropriate guardian are supported by the record, not reviewable by this court absent an abuse of discretion or clear error, and not challenged. . . . . 20.

B. The trial court was within its discretion to hear the guardianship application and to appoint Jacqueline Betancourt her father's guardian and surrogate decisionmaker. . . . . 21.

III. The trial court ruled appropriately and following precedent that the decision whether or not to discontinue life-sustaining medical treatment is for a patient to make; if the patient is incompetent, it is for the patient's surrogate decisonmaker. . . . . 23.

A. In New Jersey, the decision to continue life-sustaining treatment is for the patient to make. It comprises the right to refuse treatment as well as the right to choose to continue treatment. . . . . 24.

1. The right is a "positive" right to continue treatment, as well as a "negative" right to refuse treatment. . . . . 24.

2. The patient's condition or prognosis does not limit this right. . . . . 29.

3. The patient's right controls even if the doctor disagrees. . . . . 29.

4. Our Supreme Court has recognized that in some cases doctors may disagree with the decision to continue treatment. . . . . 30.

5. Our Supreme Court has set forth the procedure doctors must follow if they disagree with their patient's choice to continue to receive treatment. . . . . 34.

6. In New Jersey, a doctor or an institution who wishes to refuse continued treatment has an obligation to transfer the patient. Absent transfer, treatment may not be stopped. . . . . 37.

B. When the patient is incapacitated, under New Jersey law the patient's right to self-determination in choosing whether or not to continue life-sustaining medical treatment is made by a surrogate decisionmaker. . . . . 38.

1. The cases. . . . . 38.

2. The requisite procedure. . . . . 43.

a. If capable of feeling pain. . . . . 43.

b. If not capable of feeling pain. . . . . 48.

C. Out-of-state court decisions on termination of care for brain-dead patients are inapplicable. . . . . 52.

D. Other jurisdictions have refused to dismiss actions against doctors who unilaterally terminate. . . . . 52.

E. New Jersey's Advance Directive Act was enacted to enshrine and further the right to self-determination, both in choosing to prolong life and in choosing to end treatment. . . . . 53.

IV. The presumption, pervasive throughout Trinitas' brief and that of its amici, that physicians always know best what life is worth living and should have their judgment not only deferred to but legally enshrined, is, in the experience of Not Dead Yet et al., misplaced. . . . . 59.

V. Trinitas and its amici do not acknowledge the lack of consensus over whether "medical futility" is even a definable term, let alone a useful one, and that there is great debate over whether any of the situations typically referred to as "medically futile" can ever justify unilateral termination of treatment. . . . . 62.

CONCLUSION . . . . . 65.

## TABLE OF AUTHORITIES

CASES

Buck v. Bell, 274 U.S. 200 (1927) . . . . . 60.

Causey v. St. Francis Medical Center, 719 So. 2d 1072 (LA App. 2d Cir. 1998) . . . . . 53.

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Couch v. Visiting Home Care Services, 329 N.J. Super. 47 (App. Div., 2000) . . . . . .

In re Conroy, 98 N.J. 321 (1985) . . . 18, 24, 25, 28, 29, 32, 33, 34, 35, 36, 39, 40, 43, 44, 45, 46, 48, 51, 52.

In re Farrell, 108 N.J. 335 (1987) . . . . 18, 25, 26, 28, 31, 33, 42, 51.

In re Jobes, 108 N.J. 394 (1987) . . . 18, 25, 34, 35, 36, 37, 41, 42, 46, 48, 49, 50, 51.

In re Peter by Johanning, 108 N.J. 365 (1987) . . . 18, 25, 41, 48, 58.

In re Quinlan, 70 N.J. 10 (1976) . . . . . 18, 38, 47.

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STATUTES

N.J.S.A. 3B:12-1 et seq. . . . . 21.

N.J.S.A. 26:6A-1 et seq. . . . . 52.

N.J.S.A. 26:2H-2 b. . . . . 54.

N.J.S.A. 26:2H-2 d. . . . . 54.

N.J.S.A. 26:2H-2 e. . . . . 54.

N.J.S.A. 26:2H-2 f. . . . . 54.

N.J.S.A. 26:2H-54 . . . . . 56.

N.J.S.A. 26:2H-54 d. . . . . 56.

N.J.S.A. 26:2H-63 . . . . . 58.

N.J.S.A. 26:2H-63 b. . . . . 58.

N.J.S.A. 26:2H-67 . . . . . 57.

N.J.S.A. 52:27G-7.2a . . . . . 47.

REGULATIONS

N.J.A.C. 12:35-6.22(d)(2) . . . . . 38.

COURT RULES

R. 4:86 . . . . . 21.

OTHER AUTHORITY

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. . . . . 40.

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## INTRODUCTION

This appeal challenges the right of Mr. Ruben Betancourt, now deceased, to have chosen (in his case, through his court-appointed medical decisionmaker and guardian), whether or not to continue life-sustaining medical treatment.

Trinitas Hospital, the institution where Mr. Betancourt resided from July 3, 2008, until May 29, 2009, determined of its own accord to withdraw life-sustaining treatment from him. Treating him, the hospital's doctors said, was "harming" him because it was "futile," since he would not recover from the brain damage he had incurred post-operatively at Trinitas on January 22, 2008, and that he was "dying," despite having no terminal diagnosis. Mr. Betancourt was not brain dead, and the doctors could not even agree as to whether or not he would die within the year. In fact, one said, "This could go on for quite some time."

The doctors also referred to an unpaid hospital bill of $1.6 million in the context of their determination to withdraw treatment. They sought initially to withdraw dialysis, and then, respiratory ventilation, and nutrition

and hydration. Trinitas had been unable to transfer Mr. Betancourt to any other facility.

Mr. Betancourt's family opposed the hospital's decision to terminate, and in January, 2009, sought the protection of the courts. The trial court found, upon a three-day hearing record and following long-established New Jersey law, that Mr. Betancourt's daughter should be appointed his guardian and surrogate decisionmaker for medical treatment, and that Trinitas and its personnel must follow her direction in exercising her father's right to choose whether or not to continue treatment.

Trinitas appealed, arguing that the doctors alone, not the patient or his surrogate, have the right to determine when to terminate care. They also contest the daughter's appointment as guardian. Ruben Betancourt died on May 29, 2009. His daughter moved to dismiss the case, but Trinitas has opposed the dismissal.

**POSITION OF AMICI CURIAE NOT DEAD YET, ET AL.**

Amici Not Dead Yet, ADAPT, Center for Self-Determination, National Council on Independent Living, National Spinal Cord Injury Association, American Association of People with Disabilities, and Disability Rights New Jersey, (hereafter "Not Dead Yet, et al."), represent a very broad

spectrum of people with disabilities, including people with physical, developmental, and/or mental disabilities, and people whose disabilities were from birth or acquired during our lifetimes. Many are now or at some point have been labeled "terminal" by a physician. Many have had doctors threaten to remove life-sustaining treatment on an involuntary basis and have had to fight to receive continued care. As in this case, financial motives of the caregiving institution are rarely far below the surface when such threats come to pass.

All "end-of-life care" issues have been disability rights issues for decades. No one, whether disabled or currently able-bodied, is immune from the pervasive societal assumptions that affix to the disability label. Fear, bias, and prejudice against disability are inextricably intertwined in these assumptions. Our society values and desires "healthy" bodies and minds. Severe disability is viewed as worse than death. Physicians, unfortunately, are not immune from such prejudice, and, in fact, have been found to be particularly susceptible to this sort of thinking. These views and assumptions are strongly opposed by people with disabilities.

This Court is now being asked by Defendants/Appellants and their amici to overrule a trial court decision squarely

within precedent and based in factual findings from a hearing record. It is being asked to make new law, against binding authority from our Supreme Court, to create a novel right for doctors and medical institutions to unilaterally withhold life-sustaining care from patients whom they despair of curing, over the objection of patients or their surrogates and free of court oversight. It is being asked to adopt a rule-making procedure directly at odds with binding New Jersey Supreme Court precedent and with New Jersey's Advance Directive Act; to trump patient choice in favor of institutional mandate. And all on a slender record made in support of an emergency guardianship petition, without any goal on the part of the petitioner of laying the groundwork for a test case, and on behalf of a man who is now dead, preventing any further examination or factfinding.

Amici Not Dead Yet, et al., urge this Court to grant the Respondents' motion to dismiss the case as moot. The specific facts of this case, coupled with the narrow record, the extreme novelty of the Defendants/Appellants' position, and the utter lack of any record as to whether or not any other doctors in New Jersey have taken, or have even contemplated taking, such extraordinary acts as Trinitas did here, make this unfit as a test case.

Alternatively, should the Court determine to rule on this case, we urge the Court to uphold the trial court, conform to Supreme Court precedent and its proper scope for protecting the integrity of the medical profession, and refuse any step toward creating a procedure which would subordinate patient choice to unilateral imposition of a hospital committee's decision that it is time to die.

**PROCEDURAL HISTORY**

This matter is on appeal from a final decision of the Superior Court, Chancery Division, initiated by a Verified Complaint that sought temporary restraints and appointment of a family-member guardian and surrogate medical decisionmaker for Mr. Ruben Betancourt, who had severe brain damage and end-stage renal disease, and was a patient at Trinitas Hospital in Elizabeth, New Jersey, before his death on May 29, 2009.

On January 22, 2009, a hearing was held before the Chancery Division, at which time Jacqueline Betancourt, with unanimous family support, asked for a temporary injunction to restore dialysis treatment for her father, Ruben Betancourt, which the hospital wanted to terminate as "futile." Trinitas had promised the family that disconnection would not take place pending the TRO hearing. However, at the hearing, Trinitas informed the plaintiffs

and the court that, notwithstanding its promise, it had in fact removed the dialysis port from Mr. Betancourt.

The court granted the TRO, pending further hearing dates, which were held on February 17, 2009, and February 23, 2009. The court ruled in Jacqueline Betancourt's favor on both counts and ordered Trinitas to comply with her directions as to whether or not to continue her father's life-sustaining treatment. Trinitas appealed.

Mr. Betancourt died on May 29, 2009. Shortly thereafter, Jacqueline Betancourt moved to dismiss the appeal as moot. Trinitas objected. The Court withheld judgment on the motion to dismiss until after merits briefing, and set a revised briefing schedule for party and amicus briefs.

Due to the novelty of the Defendants/Appellants' assertion, amici on both sides sought and were granted leave to appear and to file briefs and participate in oral argument. This is the merits brief of amici Not Dead Yet et al., opposing the appeal, both as moot and on the merits.[1]

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[1] Amici Not Dead Yet and ADAPT were granted leave to appear, file a brief, and participate in oral argument by order of this Court on July 6, 2009. Would-be amici Center for Self-Determination, National Council on Independent Living, National Spinal Cord Injury Association, Disability Rights New Jersey and American Association of People with

## STATEMENT OF FACTS

Ruben Betancourt was a laborer all his life. For most of his adulthood he resided in Elizabeth, New Jersey. Over the course of his 37 years of marriage, he and his wife (now widow, Maria) had raised three children. All three -- Jacqueline, Robin, and Elvis -- are fully grown and employed. They work as a banker, a sheet metal worker, and a medical assistant. The two adult sons lived with their parents, and the daughter's household was next door. The family was unusually close, and all described Mr. Betancourt as an indefatigable worker and devoted husband, father, and grandfather. Robin testified that his father was his closest friend. [Testimony of Jacqueline and Robin Betancourt, Tr. III, pp. 5-11, 75-76]

Ruben developed a cough in 2008. He was diagnosed as suffering from a slow-growing tumor on thymus gland, near the heart and beneath the sternum, or breastbone. Usually such tumors are operable, as was this one, though the operation involves cutting through the sternum, opening the chest, and removing the diseased gland from its position just above the heart. If blood vessels have been implicated, they may need to be repaired, as

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Disabilities have filed a motion for leave to join in this brief contemporaneously with this brief's submission.

happened in Mr. Betancourt's case. Though invasive, the thymus operation conducted in January, 2008, at Trinitas Hospital, was successful. There is no record that a fatal recurrence of cancer was ever anticipated, much less imminent.

Prior to the operation, Mr. Ruben Betancourt had been a reasonably healthy 72-year-old, though with some diabetes and atherosclerosis. Three days after the successful thymus operation, on [date], 2008, while he was still sedated and intubated as he recovered from the incision and opening of his chest and breastbone, his daughter, Jacqueline, arrived for her daily visit on her midday lunch break. She found her father unresponsive, in bed, with his eyes rolled back into his skull. She ran to ask the doctors what had happened, and was told that, during the night, Mr. Betancourt had removed[2] his own ventilating tube, and that by the time it was replaced he had suffered brain damage due to loss of oxygen. Jacqueline, an experienced medical office assistant, said that on her earlier visits to him after the operation, she had observed her father's hands to be restrained, as they should have been to prevent precisely this injury. She doubts the hospital's version of the story as to the extubation. She was deeply

[2] This is what she was told; it is not clear that this was in fact what had happened.

concerned that the family was not notified of the extubation and brain damage for nearly twelve hours, until she happened to visit and observed it. [Testimony of Jacqueline Betancourt, Tr. III, pp. 11-14.]

Ruben Betancourt was stabilized and discharged to a series of rehabilitation hospitals, where he was weaned from the ventilator. He then lived in the Elizabeth nursing home. His brain damage was clearly profound, but the family reported that he was somewhat responsive, and notes in his chart also reflected occasional instances of awareness or responsiveness. He was, however, immobile, and developed limb wasting, bedsores, muscle contractures, and, eventually, renal failure. On developing renal failure, he was readmitted on July 3, 2008, to Trinitas, where he was reintubated and started on dialysis. [Testimony of Jacqueline Betancourt, Tr. III, pp. 15-18.]

For each dialysis treatment, three times a week, Mr. Betancourt had to be removed from the ventilator and transported through the hospital and down three flights of stairs to the dialysis room, and a hospital staffer had to manually ventilate him throughout. [Tr. II, 53.24-54.7.] Manual ventilation, or "bagging," consists of inflating and deflating a bellows-like bag by hand while holding the patient's jaw, every 4 to 5 seconds. Ideally, it takes two

or even three people to "bag" a patient properly.[3]

Mr. Betancourt lived on at Trinitas month after month. Trinitas did not wean him from the ventilator, as had the rehabilitation hospitals, nor did it transfer him to a skilled nursing facility. Mr. Betancourt was unable to take sufficient food by mouth within the time made available for feeding him, so a feeding tube was inserted. His kidney function did not return. Perhaps most distressing to the people tending him, he had developed very large bedsores because he was not moved in his bed frequently enough to prevent these ulcers. He had developed two deep stage 4 ulcers, to the bone, on his hips. More ulcers were forming on his back, since Trinitas had initially not been able to supply him with an appropriate mattress [Tr. III, 34.4-16.] or with adequate staff to rotate him frequently enough to prevent these bedsores from forming. He also developed a bone infection, which required treatment with antibiotics.

Mr. Betancourt was diagnosed as being in a persistent vegetative state. Since he had been in that state so long (seven months at the time of the hearings below), the prognosis was that he would not regain his faculties, and therefore his condition was termed a "permanent vegetative

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[3]http://rn.modernmedicine.com/rnweb/article/articleDetail.jsp?id=135255.

state." [Tr.III, 81.7-25.]

A person in a persistent or permanent vegetative state is not dead, nor brain dead. The diagnosis is applied to patients who seem completely unaware of their surroundings, and appear only to move by reflex, but have periods of wakefulness, unlike a coma patient, and, of course, unlike a brain-dead body. PVS patients do not seem to feel or experience pain. It is "not uncommon" for a PVS diagnosis to be incorrect. The most common alternate diagnosis is "minimally conscious state" or MCS. If a person has been misdiagnosed PVS and is, instead, minimally conscious, they can experience some pleasant sensations and may be able to feel pain. Bedsores, of course, can be very painful, unless the nerves have also degenerated, as can happen with diabetes. The doctors testifying at the hearing below disagreed as to whether Mr. Betancourt could feel pain. Some said yes (Millman, attending, Tr.II, 36.24-25; 37.5-9), some said no (Schanzer, neurologist, Tr.II, 83.5-7.). If he could feel pain, this would be inconsistent with the PVS diagnosis, and more consistent with a minimally conscious state, or "MCS." Both "diagnoses" are terms of relatively recent invention, used to describe patients with profound brain injury who appear not to communicate, nor to respond to their surroundings. On autopsy, such patients

are often (but not always) found to have severe injuries to the cerebral cortex. Patients diagnosed as PVS or MCS can usually breathe and even swallow on their own, but since they can only eat slowly, in tiny mouthfuls, by very time-consuming spoon-feedings, they usually cannot absorb enough nutrients by mouth within the time that caregivers are able to devote to feeding, and thus, as was Mr. Betancourt, are often intubated for feeding.

Mr. Betancourt's daughter, son Robin, and wife all testified that as far as they could tell, and they visited him every day, he could respond to their presence, did not seem to be in severe pain, but did clench his jaw and legs when medical personnel approached. [Testimony of Jacqueline, Maria, and Robin Betancourt, Tr. III, pp. 19-23, 30-33, 76-79, 85-87.] Notes in his chart described him on occasion as "awake" and "responsive." He could also respond to sound. [Tr. II, 41.6-7, 45.22-24, 46.13-14.]

As for Mr. Betancourt's prognosis, the Trinitas doctors testified that he was "dying." However, he did not have a terminal illness that the doctors could point to. Clearly he was very sick. By the time of the chancery division hearing, according to Dr. Arthur Millman, M.D., his treating physician and the Chief of Cardiology at Trinitas, Mr. Betancourt had severe brain injury due to the

respiratory extubation approximately one year before. He had diabetes, which, in his immobile state, had progressed to end stage renal failure. End stage renal failure, of course, is fatal unless treated with dialysis. He had "intermittent" COPD and hypertension, with past congestive heart failure. He had large and deep pressure sores and a bone infection. [Tr. II, 9.24-10.7; 14.2-25] Except for when he was at Trinitas, he had been able to breathe without ventilation. [Tr.III,18.11-19.1] As Dr. William McHugh, Trinitas' Medical Director, who also sits on the hospital's Prognosis Committee, said, though he admitted he had not read the medical record and chart, "This could go on for quite some time. He won't get any better, and will likely slowly get worse." Dr. McHugh confirmed that the diagnoses were: PVS, diabetes, COPD, renal failure, hypertension, past congestive heart failure, multiple major decubiti and osteomyelitis. [Tr. II, 64.13-18.] "He's been terminal for the last, frankly for the last year." McHugh, Tr. II, 66.3-4.] The doctors all agreed that Mr. Betancourt would not "recover," by which they meant that he would regain neither kidney function nor full consciousness. He could not, in that sense, be cured. The doctors disagreed as to how long he might live, and even as to whether a length-of-life prognosis was possible. [Tr.II,

71.24-72.3.] The record does not reflect any determination that Mr. Betancourt necessarily had under one year to live.

Recognizing that Mr. Betancourt was not terminally ill -- although certainly in fragile health and helpless -- cuts against Trinitas' claim that stopping care would not be killing but rather merely refusing to "prolong dying," a distinction without a real difference. This point is of considerable importance to amici Not Dead Yet et al., given the medical community's eagerness to declare disabled patients "dead" or "dying," based on perceived quality of life and lack of prospects for a full-recovery "cure," as will be discussed below, and, independently, given the dependence of many of us on assistive people and technology without which we would quickly die.

At a certain point in Mr. Betancourt's last hospitalization, his attending physician, Dr. Millman, decided that Mr. Betancourt had "had enough." At the request of Trinitas' CEO, he sought to persuade Mr. Betancourt's family to agree to discontinue dialysis. [Tr. II, 52.7-12.] They refused, stating that their father, while alive, would want to fight on until "God wills." They recalled Mr. Betancourt's watching a TV program about Theresa Schiavo and expressing agreement with her parents' efforts to continue her life and care. His family was

convinced that he would continue to seek care for them if it were instead they who were helpless, and that he would want them to do the same for him. They valued his life, even diminished, and were sure he would also value his life. They appreciated their time together, which they observed had also comforted and soothed him, for example, lowering his blood pressure when they were near, or holding his hand. [Testimony of Jacqueline, Maria, and Robin Betancourt, Tr. III, pp. 19-23, 30-36, 76-79, 85-87.]

Trinitas' prognosis committee agreed that since Mr. Betancourt could not be "cured" he should no longer be provided with kidney dialysis, because further treatment was "futile." By this point the unpaid hospital bill approached $1.6 million, as the Prognosis Committee noted. Mr. Betancourt also occasionally occupied an ICU bed needed for "acute" patients with "better survival possibilities." [Tr. II, 63.5-10.]

Dr. Millman informed the Betancourts of the $1.6 million bill and that the hospital intended to terminate the dialysis services. The Betancourts' attorney notified the hospital that he was preparing an emergent TRO application to oppose removal of dialysis. The hospital subsequently, without telling any of Mr. Betancourt's family members nor his lawyer, surgically withdrew the port

through which Mr. Betancourt had received dialysis, and cancelled his future dialysis appointments. The family found out that this had happened at the initial order to show cause hearing, when the hospital described the requested relief as "mandamus" and asserted that since the family now sought mandamus rather than an injunction – the hospital in the meantime having unilaterally changed the status quo – the family now faced a higher legal hurdle, which the hospital doubted could be met. [Tr. I, 6.11-18; 9.21 – 10.6; 11.22-12.1; 14.1-7;18.5-19.2.]

The trial judge granted the TRO. He then held two days of hearings, during which a nephrologist consulted by the Betancourts testified that he had examined Mr. Betancourt and had reviewed his medical records and was aware of the diagnosis, and that in his opinion dialysis was not harming Mr. Betancourt and was appropriate to be offered and requested. The Court appointed Jacqueline Betancourt guardian of her father and enjoined the hospital from removing life-sustaining medical care without Ruben's consent as determined by his guardian.

Trinitas filed this appeal. While the appeal was pending, Mr. Betancourt died.

**ARGUMENT**

This Court should confine itself to the questions addressed

by the trial court: May Jacqueline Betancourt be appointed as guardian of Ruben Betancourt; and may Ruben Betancourt, through his surrogate decisionmaker, choose and direct the course of his own care, and, in particular, what life-sustaining treatments, as found by the court based on this record, he will elect to continue to receive?

I. The Appellants' motion to dismiss the case as moot should be granted.

Given Mr. Betancourt's death and his family's lack of interest in pursuing the matter, the case is moot for lack of a controversy. It ought not to be revived. The presence of amici does not in itself mean that a case, though moot, should proceed. The Betancourt-supporting amici are joining merely in caution lest the Court inappropriately take this as a test case. The guardianship appointment is also now moot.

Defendants/Appellants point to instances where similar questions have been resolved even after the patient whose rights were at issue died. However, note should be taken of the motivations which propelled those cases: overwhelmingly, they proceeded either at the desire of the family to relieve similarly-situated patients and families of legal wrangling, or of the institution resisting care termination in order to secure a high-court opinion insulating it from liability. See, e.g., JFK Hospital,

Inc. v. Budworth, 452 S.2d 921 (Fla., 1984).

Of the five major New Jersey precedents -- In re Quinlan, 70 N.J. 10 (1976), In re Conroy, 98 N.J. 321 (1985), In re Farrell, 108 N.J. 335 (1987), In re Peter by Johanning, 108 N.J. 365 (1987), and In re Jobes, 108 N.J. 394 (1987), -- the patient in two died before the highest court could rule. As the Farrell Court put it: "Too many patients have died before their right to reject treatment was vindicated in court [citations to multiple cases including Conroy]. . . Even in this case--where the judicial system acted in an extremely prompt and efficient manner . . . we were unable to act in time. Mrs. Farrell died shackled to the respirator." In re Farrell, 108 N.J 335, 357-58 (1987). The Court therefore acceded to Mr. Farrell's request that it rule on the question his wife's case had presented.

In those instances where a guardian ad litem has been appointed, his view may often be that, if he can advance the public good, he has an obligation do so. For example, in Conroy, despite Ms. Conroy having died, both the guardian ad litem and Ms. Conroy's guardian pursued the case, each appealing to the next higher court. In re Conroy, 98 N.J. 321, 341-342 (1985).

That the Court can sometimes be persuaded to rule on a

matter structured from the start as a major test case, even after the death of the patient originally at issue, does not make those cases precedential for Defendants/Appellants' proposition here. They ask the Court to rule on the case of a man who died after the favorable final judgment of the trial court and before the initial briefing in this Court; whose family and guardian do not wish to proceed with the appeal; on whose sole behalf a record was made, without a guardian ad litem and narrowly addressing the immediate facts of an emergent guardianship application necessitated and driven, as this entire case has been, by the Defendants/Appellants' self-serving acts. Defendants/Appellants claim the situation is common, that doctors and surrogates are frequently at odds, yet have offered no record to substantiate that.

Further, a question is only capable of repetition **yet evading review** if the patient at issue could have been expected to die before Court could hear the case. Mr. Betancourt was not terminally ill. The fact that he did happen to die makes this case even less suitable as a test case, since it casts an aura of hindsight wisdom over the doctors' declarations that he was "dying."

The fact that Mr. Betancourt's injuries were alleged to have stemmed from negligence at the very hospital which

was seeking to terminate his care, and thereby end his life, is yet another unique aspect of this matter, making it inappropriate to serve as a test case.

Finally, disabled individuals are often subjected to pressure to agree to termination of care (and of life), or, if mentally incapacitated, to have their care and their lives terminated against their desires as expressed through their surrogates. If it is the rights of severely brain-damaged people this case would test, rather than the rights of the terminally ill, the full implications of the Court's decision will be more present to the minds of all involved if the test patient is living rather than already dead.

II. The Court was correct to determine that Mr. Betancourt is an incapacitated person, and to appoint Jacqueline Betancourt as her father's guardian.

A. The court's findings of fact that Mr. Betancourt is incapacitated and that Jacqueline Betancourt is an appropriate guardian are supported by the record, not reviewable by this court absent an abuse of discretion or clear error, and not challenged.

Trinitas itself characterizes Mr. Betancourt as suffering from brain damage serious enough to support a diagnosis of persistent vegetative state -- for all practical purposes unconscious. They also confirm Jacqueline's loving and active devotion to her father, as is also evidenced by her testimony below. There is no factual dispute on these two points: he is legally mentally

incapacitated, and she is an appropriate guardian.

B. The trial court was within its discretion to hear the guardianship application and to appoint Jacqueline Betancourt her father's guardian and surrogate decisionmaker.

In New Jersey, a guardianship petition has two components: first, establishing that there are grounds for holding a hearing as to whether or not the person alleged to be incapacitated is in fact so, and, second, an inquiry to the fitness of the proposed guardian. N.J.S.A. 3B:12-1 et seq.

To establish grounds for holding a hearing as to capacity, the Court Rule requires two physician signatures in support of a guardianship petition. R. 4:86. The signatures are to be of two doctors who have either examined the allegedly incapacitated person and found him to lack capacity, or who testify that they have been prevented from conducting such an examination. Trinitas claims that only one physician affidavit was offered by the Betancourts in support of their petition. Therefore, Trinitas seeks to have the guardianship appointment overturned -- NOT, they admit, because there was a chance that Mr. Betancourt, at best only intermittently and seemingly marginally conscious, would be found decisionally

competent;[4] NOT, they admit, because Jacqueline Betancourt is not a loving daughter, and her family's unanimous choice as guardian; and NOT, they admit, because in actuality there was any conflict of interest; but rather, they say, that, since the longer he lived the larger may have been a damages award against the hospital, therefore Jacqueline (and any other family member) allegedly had the APPEARANCE of a conflict of interest in that it might APPEAR that a loving family would subject their husband and father to suffering in exchange for money.

The trial court was well within its discretion, especially on an emergent application necessitated by the imminently lethal step threatened (and, though hidden from the petitioner, actually performed) by the hospital — the entity now retroactively challenging the proceedings -- to receive the petition, set it down for hearing, and rule on it. The second incapacity affidavit would have added nothing useful, as there was no question of incapacity.

Further, it ought not to escape this Court's attention that while the alleged POTENTIAL conflict of interest on the part of the Betancourt family has no foundation in

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[4] Some in the disability rights community disagree with guardianship proceedings as a means of addressing "competency," and most have large issues with the way in which competency rulings are often made. This case has not been chosen as a forum in which to press those concerns.

fact, the hospital's mercenary incentive for ending Mr. Betancourt's life was concrete. Every day he lived added to the unpaid bill, and, according to the hospital, potentially increased a malpractice award against it.

III. The trial court ruled appropriately and following precedent that the decision whether or not to discontinue life sustaining medical treatment is for a patient to make; if the patient is incompetent, it is for the patient's surrogate decisonmaker.

Following well-established New Jersey statutory and case law, including multiple pertinent decisions of our Supreme Court, the trial judge found -- on a record which supports the court's determination that the requested treatment a) is what the patient would have wanted, b) is not harming the patient physically, c) is sustaining the patient's life, and d) would be within what a competent physician would find reasonable to offer or to request – that the patient's doctors cannot substitute their judgment for the patient's as to what quality of life is worth continuing, nor can they ask the Court to substitute its judgment under the guise that certain doctors have chosen to call the treatment "inhumane" since the life it maintains "lacks dignity." (Like derogatory racist and sexist language, the equation of disability and indignity is anti-disability, or "able-ist," thinking.)

The trial court found that Trinitas was asking the

court to substitute the court's judgment for that of the patient and his surrogate. The trial court correctly found that in this case, under New Jersey law, it was not for the court to make the decision for the patient.

A. In New Jersey, the decision to continue life-sustaining treatment is for the patient to make. It comprises the right to refuse treatment as well as the right to choose to continue treatment.

The following six principles apply to all patients, whether or not they are incapacitated. The special procedures for effectuating the rights of mentally incapacitated patients are discussed in section III.B., below.

1. The right is a "positive" right to continue treatment, as well as a "negative" right to refuse treatment.

The right of a competent patient to refuse medical treatment has a long history at common law, dating back at least to 1891. In re Conroy, 98 N.J. 321, 346 (1985). "Though couched in constitutional terms of the right of privacy, . . . the underlying concept was an individual's right to behave and act as he deems fit, provided that such behavior and activity do not conflict with the precepts of society." Id.

In New Jersey, this includes the right to choose to continue life-sustaining treatment. Our Supreme Court has

stated unequivocally that the choice to continue to receive treatment is for the patient to make: "[A]ll persons have a fundamental right to expect that their lives will not be foreshortened against their will." Conroy, at 343, citing the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment, at 23 (1983).

> "Once someone realizes that the time and manner of death are substantially under the control of medical science, **he or she wants to be protected against decisions that make death too easy and quick** as well as from those that make it too agonizing and prolonged. . . . Deciding on a course of treatment for an incompetent patient without impinging on either of these two interests is a difficult task. To err either way--to keep a person alive under circumstances under which he would rather have been allowed to die, **or to allow that person to die when he would have chosen to cling to life**--would be deeply unfortunate." [Id., emphasis supplied; accord., In re Farrell, 108 N.J. 335, 340 (1987).]

The Court repeated this admonition in three subsequent cases, each of which dealt with a different factual circumstance, and all of which were decided in tandem, on the same day and according the same principles. In re Farrell, 108 N.J. 335 (1987), In re Peter by Johanning, 108 N.J. 365 (1987), and In re Jobes, 108 N.J. 394 (1987). "As in Quinlan and Conroy, we do not today determine whether life-sustaining medical treatment should be withdrawn from

any of the patients in these cases, but rather define **who** may make such a decision and **how** it may be made." Farrell at 341, emphasis supplied.

The argument of Trinitas and its amici that the patient's right is merely a negative one to refuse treatment and not a positive one to continue treatment, and that the hospital's and doctors' "rights" have been ignored, is therefore wrong. If the issue is whether to withdraw life-sustaining treatment, the Court has directed who can make that decision, and how. As described in the following sections, the "who" can include family, close friends, and guardians. On occasion, members of these groups do not need court approval. But the "who" can also include doctors and other interested parties, and when it does, the "how" requires court approval. The law is straightforward and clear. It recognizes the occasional appropriateness of deferring to the wishes of a treating physician or care provider when suffering can be proven, but cabins in the mechanism. In no way does it allow sua sponte action such as that which Trinitas took here.

Trinitas and its amici make two claims: First, that the patients' rights at issue in Quinlan, Conroy, Farrell, Peter, and Jobes, are merely a right to refuse treatment from a doctor who is offering it. Second, that those cases

ignore doctors' concomitant interest in refusing to provide life-sustaining care if they think the decision to extend the treatment will cause undue suffering, or, as Trinitas and its amici put it here, when the care is "futile" because it is preserving a life of such suffering that to do so is inhumane. Both arguments mischaracterize the Supreme Court's consistent approach to the issue.

The issue is not, as Trinitas puts it, whether a patient or surrogate has the right "to compel a health care professional to continue providing life-sustaining medical technology even when the continued treatment is or has become contrary to accepted health care professional standards, morals, and ethics." That is not what was decided below. The trial court found that there was sufficient evidence, including doctor testimony, to make a factual determination that dialysis was an appropriate treatment for Mr. Betancourt, that it was doing its intended job of prolonging his life, and that, in the circumstances, it was for Mr. Betancourt and his surrogate to determine whether or not his life should be prolonged.

Our Supreme Court has repeatedly described the doctor's role as being to offer counsel and information, and if requested, to prolong life, but ultimately to leave the choice whether or not to continue life-sustaining

treatment in the face of grave disability or approaching death, to the patient. Conroy, at 347. "Health care professionals serve patients best by maintaining a presumption in favor of sustaining life, while recognizing that competent patients are entitled to choose to forego any treatments, including those that sustain life." Farrell, at 351, quoting President's Commission Report.

The Court did address the situation where the providers may wish to withdraw treatment. The decisions provide a mechanism for that: any treatment provider or caregiver may seek a court's intervention if he believes that a patient's or guardian's decision is inhumane or abusive, whether that decision is to continue life-sustaining treatment or to refuse it. However, if, as in this case, the trial court finds insufficient evidence of suffering to meet the various tests described below, the court's decision cannot be reversed on the grounds that no mechanism to weigh the doctor's position has been afforded.

In fact, what Trinitas and its amici seek, is a procedure whose outcome, ultimately, always trumps the patient's directive with the doctor's own judgment. That is not consonant with due process, nor with our Supreme Court precedent.

2. The patient's condition or prognosis does not limit this right.

In Conroy, setting forth the tests which must be met before life-sustaining care could be removed from an elderly, immobile, incapacitated, but sentient[5], and not necessarily terminally ill nursing home patient, the Court said:

> It should be noted that if she were competent, Ms. Conroy's right to self-determination would not be affected by her medical condition or prognosis. **Our Legislature has recognized that an institutionalized, elderly person, whatever his physical and mental limitations and life expectancy, has the same right to receive medical treatment as a competent young person whose physical functioning is basically intact.** See N.J.S.A. 52:27G-1, declaring "that it is the public policy of this State to secure for elderly patients, residents and clients of health care facilities serving their specialized needs and problems, the same civil and human rights guaranteed to all citizens." (Id. at 355, emphasis added).

Moreover, a young, generally healthy person, if competent, has the same right to decline life-saving medical treatment as a competent elderly person who is terminally ill. Id.

3. The patient's right controls even if the doctors disagree.

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[5] "Sentient," as used throughout this brief and in the cases, means capable of feeling sensations. It does not necessarily imply capacity for conscious thought.

Trinitas and its amici say that the quintet of Supreme Court authority is inapplicable here because in those cases the doctors desired to continue treatment, and here they desired to stop. That sweeps too broadly. In some of the cases, the doctors did wish to keep treating regardless of what the patient wanted; in others they agreed that, if requested, they would withdraw treatment. While in none of the five cases had the doctors initiated the litigation themselves, let alone stopped treatment on their own say-so over the family's objection as Trinitas did here, the Court discussed what should be done when doctor and patient disargee.

4. Our Supreme Court has recognized that in some cases doctors may disagree with the decision to continue treatment.

This is not to say that a patient's right to request or forego medical treatment is unlimited. The right of doctors to refrain from providing treatments which would have no physiological effect has long been recognized.

> "Even as patients enjoy control over their medical treatment, health-care professionals remain bound to act in consonance with specific ethical criteria. We realize that these criteria may conflict with some concepts of self-determination. In the case of such a conflict, a patient has no right to compel a health-care provider to violate generally accepted professional standards. . . . A health care professional has an obligation to allow a patient to choose from among medically acceptable treatment options . . . or to reject all options.

> No one, however, has an obligation to provide interventions that would, in his or her judgment, be countertherapeutic." Farrell, at 351-52.

This dictum, unremarkable then, has been turned by Trinitas and its amici into an exception that would swallow the rule were it to be used as they propose. The use of the word "countertherapeutic," and the historical context – roughly ten years before the vogue of "medical futility" as a term meaning treatment which, while medically effective, is perhaps ethically problematic for some -- show that the Court was concerned that the patient's right to decide whether or not to forego basic life-sustaining medical treatment not morph into an ability to force doctors to provide treatment the doctors thought was unethical **due to its medical inefficacy.**

In a climate where doctors can transform from, at most, reluctantly acquiescing in a patient's decision to forego treatment despite the doctor's general preference to treat, into proponents and enforcers of an obligation to forego treatment, the words must not be read beyond their context. Medical ethics alone cannot determine at what point it becomes unacceptable to continue life-sustaining care of a living patient. "Indeed, if the patient's right to informed consent is to have any meaning at all, it must be accorded respect **even when it conflicts with the advice**

**of the doctor or the values of the medical profession as a whole."** Conroy, at 352-53.

Trinitas' entire argument rests on the dubious and falsified proposition that providing dialysis to Ruben Betancourt falls so firmly outside of what is medically acceptable that it would be unethical for any doctor to continue to maintain his life. The record in this matter does not support that contention. The utter lack of consensus as to medical futility would prevent such a record being made in any case. See, Brief of amicus curiae Professor Thaddeus M. Pope, Esq., demonstrating that "futility" does not have a commonly-accepted medical meaning. See also, Appx. to Brief of amicus curiae New Jersey Physicians, Inc. (supporting Trinitas), AMA Opinion 2.035 – Futile Care, taking the position that "futility" not be used in the context of debates over end-of-life treatment, because the word "cannot be meaningfully defined."

When the treatment in fact does perform its intended physiological effect – as ventilation supports breathing, and dialysis compensates for impaired kidney function -- and yet the worth of the effect is questioned because the worth of the life so maintained is questioned, that is not a therapeutic question. "[L]ife-and-death decisions like

these are an awesome responsibility that can be undertaken only with a profound sense of humility and reserve. The case . . . raises moral, social, technological, philosophical, and legal questions involving the interplay of many disciplines. **No one person or profession has all the answers.**" Conroy at 343; accord., Farrell, at 341.

The Court identified four State interests which may limit the patient's right to autonomous self-determination. The interests are: 1. The protection of life in general; 2. The protection of the particular patient's life (and preventing suicide); 3. Protecting the integrity of the medical profession; and 4. The protection of innocent third parties such as the patient's minor children. Conroy, at 352. Trinitas and its amici, understandably, focus on the third interest. But offering treatment and explaining the risks of refusal fulfill that obligation. Conroy, at 352.

And the Court addresses the situation where the opinions of doctor and patient differ. If the patient's right to informed consent is to have "any meaning at all," it must be followed even when it conflicts "with the advice of the doctor **or the values of the medical profession as a whole.**" Id., at 353.

As for the State interest in protecting third parties, this interest has been found to prevail when public health

or safety was at stake, and to ensure that children are not orphaned by the refusal of a parent to receive medical treatment. Conroy at 353. The interest to be protected must be rise to that level before it can overcome the patient's right to self-determination as to whether to continue living. Id. Given the other protections already in place for doctors as discussed below, their occasional personal preference to refuse to continue to provide care does not rise to this level. E.g., Jobes at 427 (treating institution's ability to refuse care was tightly circumscribed and could be overridden by the patient's right to receive care.)

5. Our Supreme Court has set forth the procedure doctors must follow if they disagree with their patient's choice to continue to receive treatment.

Trinitas and its amici assert that the trial court's holding denigrates their personal right to refuse to treat a patient. There are two objections to this.

First, the primacy of the State's interest in preserving life, both the individual life at stake and the broader principle of honoring and protecting life in general, "overrides most competing rights," such as that asserted by Trinitas and its amici -- which, if effected, would snuff out the life of a human being and degrade

respect for life in general. Conroy, at 352.[6]

Second, doctors are not at all powerless to test whether in fact their rights would be deemed subordinate. The Supreme Court explicitly opened the door of the courthouse or administrative agency to any "person," including any physician, who believes that withdrawing treatment is in the patient's best interest, as Trinitas asserts was the case here. E.g., Conroy at 383:

> "We hold that to determine whether withholding or withdrawing life-sustaining treatment from an elderly nursing-home resident who is incompetent to make the decision for himself is justified . . . the following procedure is required. A person who believes that withholding or withdrawing life-sustaining treatment would effectuate an incompetent patient's wishes **or** would be in his "best interests" should notify the Office of the Ombudsman of the contemplated action. . . . "

While this procedure is mandated for nursing home patients, it is not restricted to them. Further, as discussed below, it appears that the vulnerability which concerned the Court is not confined to nursing home patients.

Trinitas claims that its doctors should not have to be a part of treatment they consider inhumane (and unethical,

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[6] But see Jobes at 414: We "find it difficult to conceive of a case in which the State could have an interest strong enough to subordinate a patient's right to choose not to be sustained in a persistent vegetative state," quoting Peter, 108 N.J. at 380.

and "futile," because inhumane.) The physician, or any care or treatment provider, also of course has the right to request appointment as the patient's guardian for the purposes of medical decisionmaking. Neither in forcibly continuing care nor in forcibly withdrawing care, however, may the doctor act solely on his own.

> "If a disagreement arises among the patient, family, guardian, or doctors, or if there is evidence of improper motives . . . , judicial intervention will be required. We expect, however, that disagreements will be rare and that intervention seldom will be necessary. We emphasize that even in those few cases in which the courts may have to intervene, they will not be making the ultimate decision whether to terminate medical treatment. Rather, they will be acting to insure that all the guidelines and procedures that we have set forth are properly followed." Jobes at 428. (See below for a discussion of the procedures, and their applicability to the case at hand.)

The Court has also remarked that doctors' ability to phrase options, stress information, and present their own advice gives them "tremendous power" to mold and persuade the patient, even without resorting any further official intervention. Conroy, at 347.[7]

Following the procedures described in Conroy and in

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[7] See also, Robert J. Burt, The Medical Futility Debate: Patient Choice, Physician Obligation, and End-of-Life Care, Journal of Palliative Medicine, Vol 5, No. 2, 2002. Professor Burt, of Yale Law School, maintains that the court system is a necessary counterweight to the doctors' power if consultation and negotiation in these situations is to have any real meaning.

Jobes, as discussed below, a doctor may seek the court's intervention if he or she believes that a patient's decision or a surrogate's direction to continue treatment is harming the patient, is against the standard of care, or otherwise violates accepted medical principles. The fact that Trinitas and its doctors did not follow the direction of our Supreme Court as to what steps should be taken when a physician feels that continuing treatment is not in the patient's best interests and is harming the patient, does not mean that such direction does not exist. "Whenever a health-care professional becomes uncertain about whether family members are properly protecting a patient's interests, termination of life-sustaining treatment should not occur without the appointment of a guardian." Jobes at 419. The steps are addressed at more length in section III.B., below.

6. In New Jersey, a doctor or an institution who wishes to refuse to continue treatment has an obligation to transfer the patient. Absent transfer, treatment may not be stopped.

As set forth in the brief of amicus curiae Prof. Thaddeus M. Pope, at 22, the New Jersey Administrative Code requires that any medical licensee who wishes to stop providing life-sustaining treatment must arrange for a transfer of the patient to an appropriate alternative facility, and if such transfer is not possible, may not

discontinue treatment. N.J.A.C. 12:35-6.22(d)(2).

As discussed at length by Professor Pope, the assertion by Trinitas and its amici that an inability to transfer a patient evinces a standard of care against continuing treatment is incorrect. Pope Brief, at 20. Facilities refuse to accept patients for many reasons having nothing to do with a standard of care, chief among them cost. "Transferring the Ethical Hot Potato," 17 Hastings Center Report 20-21 (Feb., 1987).

B. When the patient is incapacitated, under New Jersey law the patient's right to self-determination in choosing whether or not to continue life-sustaining medical treatment is made by a surrogate decisionmaker.

1. The cases:

Our Supreme Court first addressed in 1976 how to effectuate the right of self-determination when a person is unable to respond to communication and therefore is prevented from exercising the right directly. In re Quinlan, 70 N.J. 10 (1976), determined that it would be legal for the right to be effectuated by a surrogate decisionmaker, who would decide not on the basis of what the surrogate would want, but on the basis of what the patient would choose if he could. While Karen Ann Quinlan was both fed by tube and breathing on a respirator, the case centered on withdrawal of the respirator as an artificial apparatus which she allegedly would not have

wanted to keep her alive. It was presumed that without the breathing assistance she would die almost immediately. In fact, when it was removed, she lived for nearly ten more years, still fed by the tube. Her parents later said that they had never considered removing the tube once it became apparent that she could breathe on her own. They distinguished between a machine — the ventilator — "artificially" maintaining her life, and the feeding tube that was the means by which, continuing to live on her own "naturally," she was fed. This distinction was the occasion for further examination by the Supreme Court, first in In re Conroy, in 1985. Ultimately, the Court refused to draw a line between respiration and feeding — both of which, like dialysis, can be characterized as life-sustaining interventions, and both of which are immediately necessary to preserve life in patients who cannot breathe, or eat, on their own. Conroy, at 372.

Claire Conroy was declining both mentally and physically due to extreme old age, while resident in a nursing home, and she appeared to be suffering, but was neither fully unconscious nor dependent on a respirator. She lay curled in bed, essentially unresponsive, apparently deeply demented, moaning apparently in pain, incontinent, and fed by tube. Her nephew, whom she had consented to be

appointed her guardian before her long deterioration had progressed, and who demonstrably had her best interests at heart, sought to have the tube removed, although she was not suffering from a terminal disease.[8] The Conroy Court, therefore, faced a situation similar to Mr. Betancourt's, to the extent that the assertion of Dr. Millman that Mr. Betancourt was capable of suffering pain is given credence.

The Court stated that in exercising the right to self-determination on a patient's behalf, substitute decision-makers must seek to respect "simultaneously **both** aspects of the patient's right to self-determination-- the right to live, and the right, in some cases, to die of natural causes without medical intervention." Id. at 356.

In three subsequent cases – Peter, Farrell, and Jobes,

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[8] The diagnosis and prognosis of a "terminal condition" is inherently uncertain in any case. Timothy E. Quill et al., Sounding Board: Care of the Hopelessly Ill, 327 New Eng. J. Med. 1380, 1381 (Nov. 5, 1992) ("[W]e acknowledge the inexactness of such prognosis [of imminent death]"). Most of the 9,000 seriously ill people tracked in the famous SUPPORT study were in the "middle muddle" of prognoses, bad enough to be at risk of death but good enough to hope for long term survival. Doctors were wrong about who was dying and who was not close to half the time. A significant percentage of the patients whom doctors thought had no more than a 50% chance of living six more months, lived much longer. Half of those who died while conscious were in untreated pain; advance directives, if found, were vague; and doctors did not know whether patients wanted DNR orders. John Horgan, "Seeking A Better Way to Die" 276 *Scientific American* 100 (May 1997).

supra, decided together by the Supreme Court in 1987 -- the Court addressed related, yet subtly different factual scenarios. Still, the core principle remained:

> "Embarking on this task, we are mindful that **the patient's right to self-determination is the guiding principle in determining whether to continue or withdraw** life-sustaining medical treatment; that therefore the goal of a surrogate decision-maker for an incompetent patient must be to determine and effectuate what that patient, if competent, would want; and that the court does not decide whether to withdraw life-supporting treatment. Rather, our role is to establish for those who make that decision criteria that respect the right to self-determination and yet protect incompetent patients." Peter, at 399. Emphasis added.

In Peter, the Court set forth the decision-making procedure for a likewise elderly person, though one whose physical condition was better than Ms. Conroy's, but whose brain was severely damaged and who was apparently insentient (similar to Mr. Betancourt if Dr. McHugh was right in his perception that Mr. Betancourt could not feel pain nor suffer), and who had made her desire not to be kept alive well known before she became incapacitated. In that instance, said the Court, with a clear prior directive, a family member or even a close friend may direct the decision on the patient's behalf, without the need for court involvement. The case anticipated and inspired New Jersey's advance directive act.

In Jobes, the Court addressed the case of a patient

who, while young and otherwise not ill, had, upon multiple, lengthy, and exceedingly thorough examinations — in contrast with the two brief, perfunctory "examinations" of Mr. Betancourt by Dr. Schanzer [Tr. II, pp. 79–86]-- been determined to be so brain damaged as to be insentient. Mrs. Jobes had suffered a blood clot to her brain during surgery. Mr. Betancourt's case could fall within the Jobes model if the diagnosis of PVS is correct. In that case, the extent of his physical debilitation and suffering cannot weigh in the balance, since he would be incapable of perceiving it. The Court stated that family members were presumptively the proper surrogate decisionmakers, but that if a doctor believes that family member surrogate decisionmakers are not acting in the patient's best interests, the doctor may act contrary to the family's directives. However, in that case, the doctor must petition the Court for appointment of a guardian before terminating any life-sustaining treatment. Jobes at 419.

In Farrell, the Court confronted a person who was ill with a severely degenerative disease (ALS), which, while leaving her mental capacities intact, had destroyed her muscle control so extensively that without artificial respiration she would die quickly of suffocation. After having experienced the ventilator for a lengthy time, she

did not tolerate it, and expressed a desire to be rid of it even if the alternative was to die. While Farrell explicitly postulates universal principles of self-determination that apply in all situations, the specific facts are not before us here, since Mr. Betancourt was unquestionably incapacitated and possibly insentient.

2. The requisite procedure:

a. If capable of feeling pain:

For a patient such as Claire Conroy – and, if Dr. Millman's assessment that he could fee pain was accurate, Mr. Betancourt[9] -- the Court set forth three approaches: the subjective test, where there is clear evidence as to what the patient would have wanted, Conroy at 360-61, the limited objective test, where there is some evidence of suffering and some evidence as to what the patient would have wanted (arguably, the situation here), Conroy at 365, and the fully objective test, where, despite a lack of evidence as to what the patient would have wanted, evidence of suffering is so overwhelming as to permit the decision to discontinue treatment to be made on that basis alone,

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[9] While the Court found that Mr. Betancourt was in a persistent (or permanent) vegetative state, the risk of misdiagnosis, and the harm done to the patient if he is treated as insentient when he is in fact sentient, militates in favor of this Court assuring itself that under Conroy, as well as under Jobes, the trial court made the correct decision.

Conroy at 366.

**The Court held that life-sustaining treatment may ONLY be withheld or withdrawn from an incompetent but potentially suffering patient when it is clear that the particular patient would have refused the treatment under the circumstances involved.** Conroy, at 360. "The question is not what a reasonable or average person would have chosen to do under the circumstances but what the particular patient would have done if able to choose for himself." Id.

**The sole exception — if the patient may be in pain -- is when evidence of suffering in a patient established to be rapidly approaching death, justifies, in the name of humaneness, the State's invocation of its parens patriae authority to step in and protect the patient.** The suffering must either be combined with some evidence that the patient would have preferred to die rather than to endure it, or be so severe that anyone would rather die than endure it. Conroy, at 364-65.

This applies to anyone attempting, as Trinitas did here, to invoke considerations of **humaneness** to justify termination of life-sustaining medical treatment. It must be kept in mind that the Trinitas physicians said that they had a right to withdraw treatment because it fell beneath

the standard of care; that it fell beneath the standard of care because it was futile; that it was futile because it was prolonging a life; that it was wrong to prolong that life because the life was perceived be the doctors to be without dignity and possibly in pain. The asserted lack of dignity and possible pain underlay the "right" asserted.

> Q.: Doctor [William McHugh, Trinitas Medical Director], in your opinion, is any of the treatment that's currently being administered to this patient doing him harm?
> A.: Only in the sense that we're continuing to treat a hopeless situation . . . It all seems ineffective because it's not getting us anywhere. . . . I think we're doing damage here . . . We're allowing a man to lay in bed and really deteriorate virtually right under our eyes . . .
> Q.: So your opinion is that to continue to keep this man alive is doing him harm?
> A.: Yes.
> [Tr. II, 67.10-68.7]

When, therefore, for humane reasons, physicians (or anyone else) seek to terminate treatment, a guardian must first be appointed. Conroy at 381-83. The guardian is then empowered, if provided with sufficient supporting evidence of suffering, to make the determination (with notice to the Ombudsman if the patient is elderly and residing in a nursing home.) Id. Since, in New Jersey, a treating physician has standing to petition the Court to be appointed guardian of a patient, this procedure was available to the doctors at Trinitas. They chose not to avail themselves of it. Naturally, invoking the court's

jurisdiction is more cumbersome than merely acting of one's own accord. Nonetheless, it is what the law requires.

And the Court was extremely concerned to make sure that the process would in fact be cumbersome. It wished to protect patients from the very sorts of overreaching suffered by Mr. Betancourt at the hands of his doctors and hospital. In Conroy, the Court presumed that it was nursing home patients who would be more likely to be victimized in this way than hospital patients, Id. at 375, but the facts in this case show that the Court's concern was directed too narrowly.

Ironically, in Jobes the Court remarked, "We recognize that generally, because of the presence of attending physicians and prognosis committees, hospitals afford greater protection against the premature termination or undue prolongation of life-support measures." Jobes at 428. That was then. Any institutionalized patient, clearly, is now at risk, whether institutionalized in a hospital or in a nursing home, and in need of the protection the Court sought to ensure by requiring that before treatment could be terminated on the justification of ending suffering, evidence would have to be mustered, notice given to the next of kin as provided in the guardianship statute (and as was NOT done by Trinitas, who

disconnected the dialysis port in stealth), and the oversight of the court invoked.

The Court was also of the mind that a Prognosis Committee would act as a damper on any "premature" termination of life-sustaining treatment. These committees were envisioned in Quinlan as deliberative bodies designed as a backstop to validate the treating physician's concurrence with the surrogate that treatment could be withdrawn. In re Quinlan, 70 N.J. 10, 55. As happened here, the introduction of dollar signs into the deliberations of prognosis committees threatens to convert those committees -- instituted as bodies equipped with the knowledge to help guide patients and their families on THEIR choices-- instead into Star Chamber tribunals, rendering unreviewable capital verdicts without due process.

In fact, the Court set forth an additional layer of protection. In addition to having a guardian appointed, the person seeking to terminate treatment as "in the best interest" of a person over the age of 60 would also have to notify the Ombudsman charged under N.J.S.A. 52:27G-7.2a with protecting the aged, and secure his approval. The Ombudsman process involves the certifications of two physicians, in addition to various other procedural steps.

This is all necessary, says the Court, because of the risk that the persons advocating for cessation of treatment, while acting in good faith, might not have sufficiently separated their interests from those of the patient in whose interests they purport to act. Id. at 375-79. This includes doctors.

Given that, in this case, Trinitas and its affiliated physicians had a compounded financial reason for desiring Mr. Betancourt to die – the accumulating unpaid bill and the accumulating pain and suffering award in the prospective medical malpractice case, as they themselves note -- the Court's disquiet would seem to be justified.

b. If not capable of feeling pain:

Since a person with a diagnosis of unconsciousness sufficient to preclude sensation of pain does not, it is commonly presumed, have suffering to weigh against prolonging life, and likewise is presumed to lack the capacity to enjoy life, the Court set forth slightly different standards for a patient in that situation, depending upon the patient's known prior wishes. In re Peter by Johanning, 108 N.J. 365 (1987); In re Jobes, 108 N.J. 394 (1987). A diagnosis of "persistent vegetative state" is the hallmark of such a patient. It must be kept in mind that this diagnosis is merely descriptive of how

the patient appears to observers, and of the progressively lower probability that the patient will emerge from this state.

"Because of the unique problems involved in decisionmaking for any patient in the persistent vegetative state, we necessarily distinguish their cases from cases involving other patients. Accordingly, in Peter we held that neither the life-expectancy test [since the patient may have many years of life expectancy] nor the balancing tests set forth in Conroy [since the patient presumably can feel neither suffering nor any positive emotions] are appropriate in the case of a persistently vegetative patient. . . . Those holdings are equally relevant in this case. In any case involving a patient in the persistent vegetative state, we look instead primarily to Quinlan for guidance." Jobes at 413.

For a patient in this state, the Court said that the law directed an approach "intended to ensure that the surrogate decisionmaker effectuates as much as possible the decision that the incompetent patient would make if he or she were competent. Under the substituted judgment doctrine, where an incompetent's wishes are not clearly expressed, a surrogate decisionmaker considers the patient's personal value system for guidance. . . . Almost

invariably the patient's family has an intimate understanding of the patient's medical attitudes and general world view and therefore is in the best position to know the motives and considerations that would control the patient's medical decisions. . . . We believe that a family member is generally the best choice." Jobes at 415.

Medical authorities also have recognized that family members are appropriate surrogate decisionmakers for incompetent patients. Id. at 418.

If there are no close family members, and the patient has not left clear and convincing evidence that he or she intended another relative or a nonrelative friend to make surrogate medical decisions in the case of his or her incompetency, then a guardian must be appointed, and the Quinlan procedure followed. Id. When the guardian, the family, and the attending physician concur that life support should be withdrawn from a hospital patient in a persistent vegetative state, they must secure the confirmation of a hospital prognosis committee that there is no reasonable possibility that the patient might recover to a cognitive sapient state. Id. at 420-21. The prognosis committee's role is to confirm the agreement of the family and the treating physician, NOT to overrule the surrogate.

If there is a dispute among the members of a patient's family, the guardian and the physicians, any interested party can invoke judicial aid to insure that the guidelines are properly followed and that the patient is protected. Id. at 423-24.

The doctors' primary role is to provide information and expertise in assessing the degree of suffering and the patient's life expectancy. Conroy. at 365-66. See, Farrell at 362-63, O'Hern concurring:

> "The President's Commission stresses the role of the physician in this decisionmaking process: The individual health care provider is likely to help dying patients most by maintaining a predisposition for sustaining life (while accepting that prolongation of dying may serve no worthwhile purpose for a particular patient). **Indeed, this favoring of life is part of society's expectation regarding health care professionals.** Commonly, it is supported by a personal belief or value commitment and by a recognition of the needs of dying patients for reassurance about the worth of their own lives."

The Court expects doctors to provide the very sort of assessment they made of Mr. Betancourt in this case, but in the setting where it is the guardian, not they, who must make the ultimate decision. Conroy, at 365-66. The Court expects the doctors to be learned witnesses, or, possibly, even parties (if they seek the guardianship), but not would-be "angels of mercy" dragged into court after taking it upon themselves to cease treatment.

The Court went so far as to say that even in the context of severe pain, life-sustaining treatment should not be withdrawn from an incompetent patient who had previously expressed a wish to be kept alive in spite of any pain that he might experience. Id. at 367. This directive form our Supreme Court cuts directly against Mr. Betancourt's doctors' claims that they were acting within the law to spare him suffering. The Court also explicitly rejected arguments such as that made by Trinitas and its amici about acting to preserve the patient's dignity or quality of life, since the power to make decisions about other people's lives, "would create an intolerable risk for socially isolated and defenseless people suffering from physical or mental handicaps." Id.

C. Out-of-state court decisions on termination of care for brain-dead patients are inapplicable.

Trinitas and its amici cite to various cases where the patient at issue was brain dead. These cases are irrelevant. Under New Jersey law, a brain dead patient is dead and may be removed from life support, with the exception of a patient whose religious beliefs preclude cessation of life support prior to the failure of the heart and blood circulation. N.J.S.A. 26:6A-1 et seq.

D. Other jurisdictions have refused to dismiss actions against doctors who unilaterally terminate.

Trinitas and its amici also make much of two out-of-state cases, where, they assert, Courts upheld unilateral withdrawal of care by medical practitioners.[10] Each of those cases was brought against the physicians to recover damages for medical malpractice, wrongful death, and associated causes of action articulated in an attempt to provide a civil remedy for what the doctors had done. In both cases, some claims were dismissed, and others were allowed to proceed. In neither case did the Court endorse what had happened, and in both cases the doctors' deeds were found to be actionable.

E. New Jersey's Advance Directive Act was enacted to enshrine and further the right to self-determination, both in choosing to prolong life and in choosing to end treatment.

The New Jersey Advance Directives for Healthcare Act was passed four years after the Farrell/Peter/Jobes cases. The Ombudsman for the aged referred to in those cases was its legislative sponsor. While its provisions are inapplicable to Mr. Betancourt, who had never executed an advance directive, Trinitas and its amici seek to use it in two ways. First, they claim that the Act permits them, to end Mr. Betancourt's life for him. This is a gross

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[10] Rideout v. Hershey Medical Center, 30 Pa. D & C 4th 57 (C.P. Dauphin Ct. 1995); Causey v. St. Francis Medical Center, 719 So. 2d 1072 (LA App. 2d Cir. 1998).

misreading of the Act, as described below. They also claim the Act privileges their position, likewise wrong.

The Act finds and declares that:

> ". . . For some individuals the possibility of extended life is experienced as meaningful and of benefit. For others, artificial prolongation of life may seem to provide nothing medically necessary or beneficial, serving only to extend suffering and prolong the dying process. This State recognizes the inherent dignity and value of human life and within this context recognizes the **fundamental right** of individuals to make health care decisions to have life-prolonging medical or surgical means or procedures **provided, withheld, or withdrawn.**" N.J.S.A. 26:2H-2 b.

The Act is structured so as to prefer life while leaving the ability to choose to refuse care to the patient. The Act follows the Court in recognizing that the State has an interest in preserving life, in preventing suicide, in protecting innocent third parties (minor children, explicitly), and in

> "safeguarding the ethical integrity of the health care professions, individual professionals, and health care institutions, and maintaining public confidence and trust in the integrity and caring role of health care professionals and institutions. Finally, society has an interest in ensuring the soundness of health care decision making, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice." N.J.S.A. 26:2H-2d.

The Act recognizes the right of doctors to be consulted participants in the decisionmaking. N.J.S.A. 26:2H-2e. and f.

See, for example, Governor Florio's signing statement in the legislative history:

> "Governor Jim Florio today signed what experts agree is the most comprehensive, sensible 'living will' legislation in the nation. The law is designed to allow people the right to decide in advance what type of health care treatment they **would - or would not** - want if they became terminally ill or comatose. New Jersey was one of only five states in the country not to have such legislation. . . ."

Governor's signing statement, N.J.S.A. 26:2H-1 et seq. (emphasis added), available at: http://www.njstatelib.org/NJLH/lh1991/L1991c201.pdf

To the extent any of the Act's provisions could be misconstrued as permitting doctors to override patient directives in the name of "futility," the State of New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (The New Jersey Bioethics Commission) has written a summary of the Act, as follows:

> Is my doctor obligated to talk to my health care representative?
>
> Yes. Your health care representative has the legal authority to make medical decisions on your behalf, in consultation with your doctor. Your doctor is legally obligated to consult with your chosen representative **and to respect his or her decision as if it were your decision.**
>
> . . .
>
> <u>Can I request all measures be taken to sustain my life?</u>
>
> **Yes.** You should make this choice clear in your advance directive. Remember, a directive can be used to request medical treatments as well as to refuse unwanted ones.
>
> . . .

> Does my doctor have to carry out my wishes as stated in my instruction directive?
>
> If your treatment preferences are clear your doctor is legally obligated to implement your wishes, unless doing this would violate his or her conscience or accepted medical practice. **If your doctor is unwilling to honor your wishes he or she must assist in transferring you to the care of another doctor.**[11]
>
> . . .

Advance Directives for Health Care, Planning Ahead for Important Health Care Decisions http://www.state.nj.us/health/healthfacilities/documents/ltc/advance directives.pdf

The Act established safe harbors for medical personnel opposed to withdrawing or denying care even if requested to do so for patient. No parallel safe harbor was established for the reverse position. N.J.S.A. 26:2H-54. For example: "Nothing in this act shall be construed to require a physician, nurse or other health care professional to begin, continue, withhold, or withdraw health care in a manner contrary to law or accepted professional standards." N.J.S.A. 26:2H-54. d. The language, repeated in various places in the statute, limits the following two possibilities -- first, that the advance directive statute is not to be used, for example, to circumvent or add to the law on refusal of blood

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[11] Ironically, two of the amici curiae supporting Trintas' claim that doctors have the right to unilaterally withdraw treatment **absent transfer**, the Medical Society of New Jersey, and the New Jersey Hospital Association, are among the entities endorsing the brochure. The brochure comports with the law requiring transfer, see bolded section of text, above.

transfusions or emergency medical care on the basis of religious preference. It "shall not be construed to abridge" any such right, but must not be construed to expand it, either. Second, the language seeks to ensure that patients will not be able to direct their physicians to perform quackery.

Trinitas and its amici claim that the language confers on medical providers the power to terminate care and life on their own mere say-so. But to read it that way would be to render the entire statute superfluous.

N.J.S.A. 26:2H-67 lists certain medical situations, including unconsciousness with a prognosis of permanency, and takes pains to say that, **even with** an advance directive, these are the **only** situations where life sustaining care may be withheld. Trinitas' amici NJHA, CHPNJ, and MSNJ tread close to misleading the Court by their failure to cite the critical, limiting phrase, "Consistent with the terms of an advance directive and the provisions of this act . . ." when they assert, in their Brief at 29-30, that the mere presence of any enumerated situation frees the physician to terminate care in the absence of an advance directive. That is the direct opposite of what the Act provides.

The lodestar of the Act is that it is for the patient

to determine when "medically appropriate measures utilized to sustain life" **will or will not** be provided. N.J.S.A. 26:2H-63. The statute is replete with instructions to err on the side of providing care. For example, at 26:2H-63 (b): "Notwithstanding any other provision of this act to the contrary, if a patient who lacks decision making capacity clearly expresses or manifests the contemporaneous wish that medically appropriate measures utilized to sustain life be provided, that wish shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive."

"Accepted professional standards" does not mean whatever the treating physicians think is best, nor even what one intramural ethics or prognosis committee thinks is best. If competent physicians can disagree as to the acceptability of the intervention, as they did in this case, withdrawing it unilaterally is not an "accepted professional standard." Peter, at 409, discussing the fact that doctors' opinions may vary and concluding, "While we recognize the gravity of the responsibility to evaluate medical evidence in withdrawal-of-treatment cases, we believe that our traditional confidence in the factual determinations made by our trial courts is as appropriate

in this as in other contexts."

IV. The presumption, pervasive throughout Trinitas' brief and that of its amici, that physicians always know best what life is worth living and should have their judgment not only deferred to but legally enshrined, is, in the experience of Not Dead Yet et al., misplaced.

Doctors often acquiesce in societally-mediated feelings that death is preferable to disability. When conscious, though disabled, patients can come to be seen as candidates for euthanasia, how much easier is it to project similar fears onto people with severe brain damage.

The question of whether doctors should be permitted, on their own initiative, to end life-sustaining treatment when, in their opinion, the patient has "had enough," must be seen against the background of the United States' long and tragic history of state-sanctioned discrimination against the disabled. The Supreme Court has acknowledged that at least one of the forms of this discrimination, the practice of withholding lifesaving medical assistance by medical professionals from children with severe disabilities, demonstrates a "history of unfair and often grotesque mistreatment" arising from a legacy in this country of "prejudice and ignorance" and continuing well into the 20th century.[12]

[12] City of Cleburne, Texas v. Cleburne Living Center, 105 S. Ct. 3249, 3262 (1985) (Stevens, J., joined by Burger, C.J.,

Throughout history, state officials, with the support of the medical community, have authorized the sterilization of people with disabilities.[13] Such attitudes, unfortunately, are not completely in the past.[14]

When medical professionals and the media use phrases like "imprisoned by her body," "helpless," "suffering needlessly," and "quality versus quantity of life," purportedly in a humanistic and compassionate way, they are really expressing fear of severe disability and a very misguided condemnation: "I could never live like that." For example, our society often translates these emotions into a supposedly rational social policy of assisted suicide or "passive euthanasia" homicide. Whenever permanent disability is [defined] as the problem, death is the solution.... [T]he wish to die is transformed into a desire for freedom, not suicide. If it is suicide at all, it is 'rational' and, thereby, different from suicides

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concurring), 3266 (Marshall, joined by Brennan & Blackmun, JJ., concurring).

[13] Buck v. Bell, 274 U.S. 200, 207 (1927).

[14] See M. Louis Offen, Dealing with "Defectives": Foster Kennedy and William Lenox on Eugenics, 61 Neurology 668 (Sept. 2003)

resulting from [the same] emotional disturbance or illogical despair [that nondisabled persons face]."[15]

The medical profession is not immune to these erroneous assumptions. Research shows that doctors frequently project the "quality of life of chronically ill persons to be poorer than patients themselves hold it to be, and give this conclusion great weight in inferring, incorrectly, that such persons would choose to forgo life-prolonging treatment."[16] As long as physicians believe that a person with a severe disability has a "life unworthy of living." lethal errors and abuses will occur.

V. Trinitas and its amici do not acknowledge the lack of consensus over whether "medical futility" is even a definable term, let alone a useful one, and that there is great debate over whether any of the situations typically referred to as "medically futile" can ever justify unilateral termination of treatment.

Professor Pope, a noted authority on the topic of "medical futility," has submitted a brief as amicus curiae, wherein he discusses the lack of consensus at length. Amici Not Dead Yet, et al. would add their observation that the concept of cost seems inextricably linked with the desire of physicians to end care, and that the publications of various medical societies and councils differ in their

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[15] C.J.Gill, Suicide Intervention for People With Disabilities: A Lesson in Inequality, 8 Issues in Law & Med. 37, 39 (1992).

[16] S. Miles, Physicians and Their Patients' Suicides, 271 J.A.M.A. 1786 (1994).

approaches. For example, the American Council of Obsteticians and Gynecologists holds that "patient and family values regarding treatment options and the default position of maintaining life ordinarily should take priority" over "physician's opinions" and "unilateral refusal." American Council of Obstetricians and Gynecologists, Committee Opinion No. 362: Medical Futility. The ACOG candidly acknowledges that when "society" sides with physicians in deeming care futile, it does so because of the cost of treatment. Id. In fact, the **only** time patient and family direction should be outweighed is when "claims of reasonableness and equity in the distribution of resources are so powerful that the views of caregivers, the institution, and society will prevail." Id.

The American Thoracic Society, to give another example, appears to take multiple positions:

> Common Approaches in Critical Care: " . . .Any or all procedures and devices can be withheld or withdrawn at any point **based upon the wishes of the patient** or of the family when the patient is not able to make his or her wishes known. . ."
>
> Withdrawal of Life-Sustaining Treatments: "After initial attempts to treat a critical illness, some patients do not respond or their condition worsens. Sometimes, patients have been started on life-sustaining treatments, such as a breathing machine and CPR, before their wishes or a living will comes to light. In these situations, after careful discussions with doctors, these treatments can be stopped and other treatments begun to make certain the dying patient is

comfortable. . ."

> Medical Futility: "Doctors are not legally required to offer treatments that they believe are 'medically futile'-- that is, will not improve the patient's medical condition or prevent it from getting worse. If doctors believe that CPR or mechanical ventilation is only likely to prolong dying and suffering, they may make these views known to patients or their families. If the patient (or family member) believes the doctor is wrong, he or she can get a second doctor's opinion, a consultation of the hospital ethics committee, or simply ask the doctor to recommend another doctor to take charge of care. Most doctors will not be offended if politely asked for any of these choices, and it may help a loved one in this position to feel more comfortable to hear, from additional experts, that medical care is futile (that is, only likely to prolong dying and suffering)."

www.thoracic.org/sections/clinical-information/critical-care/patient-information/index.html

The first statement confirms definitively that care will only be withdrawn at the patient's direction. The second statement strongly implies that care will only be withdrawn if the patient's wishes or directive to do so "come to light," and after "careful discussions" with doctors. It would be difficult to draw an inference that the doctors might be the ones to withdraw care on their own hook. The third statement is the only one of the three that could raise a question as to what is actually going on. It does not come right out and state that doctors will disconnect respiratory ventilation on their own initiative and against the wishes of the patient, but it sidles

closer. The inescapable conclusion is that friction within the Thoracic Society prevented a consistent approach to patient information.

If doctors themselves cannot define futility, cannot agree as to when termination of treatment is appropriate, and continue to debate the attendant terminology, how can the Court justify permitting doctors, acting on their own, to end someone's life on the premise that to sustain that life would violate a "standard of care" because it is "futile"?

In New Jersey, our Supreme Court has wisely directed that these determinations, if contested, may not be unilaterally resolved in favor of the treating physician, but must be addressed in our courts, where full and appropriate notice must be given, everyone may be heard, and the protections of due process will obtain. Once a trail court has ruled on the matter, the judgment is reviewable under our accepted standards of judicial review. This fully protects the "right" to cease "inhumane" treatment asserted by Trinitas and its amici. But their desire to be free to act in these matters without court interference does not remotely justify reversing the well-founded decision below.

## CONCLUSION

For the foregoing reasons, amici curiae Not Dead Yet, ADAPT, Center for Self-Determination, National Council on Independent Living, National Spinal Cord Injury Association, American Association of People with Disabilities, and Disability Rights New Jersey, respectfully request that the Court grant the Respondent's motion to dismiss this case as moot, or, in the alternative, affirm the decision of the trial court.

Respectfully submitted,

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