Parents’ Right to Know—Finally

For the first time in the history of California, the people will have an opportunity to vote on a measure relating to abortion. Thanks to the efforts of thousands of pro-life, pro-family Californians, the Parents’ Right to Know and Child Protection Initiative (PRKCP) has qualified for the state ballot and will top the list of initiatives on the ballot this November. If passed, this initiative will ensure that a parent is notified at least 48 hours before his or her minor daughter receives an abortion.¹

Although California has arguably the most pro-abortion laws in the country, this is historically due primarily to court decisions. By the time of the United States Supreme Court decision in Roe v. Wade in 1973, California state courts had already read various restrictions out of the admittedly lax 1967 Therapeutic Abortion Act. Roe finished the job of gutting that law.

After Roe, the state courts took over again, creating a constitutional “right to abortion” misleadingly premised on the “right of privacy” initiative passed by voters in 1972. (This initiative was approved by voters only to ensure that personal information would not be misused.) Relying on this phony constitutional right to abortion, the courts went beyond U.S. Supreme Court precedent to hold that the state must fund abortions with taxpayer dollars and that state law could not require minors to obtain a parent’s consent before obtaining an abortion.

More recently, the state legislature has become a virtual arm of Planned Parenthood, California Abortion Rights Action League, and their ilk, with the result that pro-abortion legislation, such as the California Freedom of Access to Clinic Entrances Act, the Reproductive Rights Law Enforcement Act, and the Reproductive Privacy Act have sailed through. Shockingly, it has been over fifteen years since any bill restricting abortion in any manner or degree has gotten out of a legislative committee. It has been over fifteen years since any measure restricting abortion has received an up or down vote on the floor of either house of the legislature.

Through all of this, the direct voice of the people has not been heard in the manner provided for in the initiative process. The people never voted for abortion, much less unlimited, taxpayer-funded abortion on demand. With the Parents’ Right to Know initiative, for the first time the people will tell the legislature, the governor, and the courts what they think of the regime of unfettered abortion that has been thrust on them.

Because of California’s size, passage of

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² Schiavo v. Schindler (Fla.)—After denying the Schindlers’ motion arguing that starving Terri to death would violate her religious beliefs and be contrary to her wishes as a Catholic, Judge Greer set the date of March 18 for removal of food and water. As the date neared and the state court appeals were all exhausted, efforts were made in both the Florida state legislature and the U.S. Congress to pass legislation to help Terri and other similarly situated individuals. No action was taken in the state legislature. Congress issued an investigative subpoena, but Judge Greer ignored it, and ordered that Terri’s tube be removed. Two days later, Congress passed a law allowing the Schindlers to bring an action in federal court presenting the evidence of Terri’s rights being violated. However, rather than looking at the issues
LLDF Lawyers Represent Taxpayers Groups in Attack on California Stem Cell Research and Cures Act

In November 2004, California voters passed Proposition 71. This proposition created the California Institute of Regenerative Medicine and its governing body, the Independent Citizens’ Oversight Committee (“ICOC”).

On behalf of two taxpayers’ groups, People’s Advocate and National Tax Limitation Foundation, LLDF’s lawyers filed a Petition for a Writ of Mandate in the California Supreme Court seeking to have the Act establishing the ICOC declared to be in violation of Article XVI, Section 3, of the California Constitution because the state could not exercise exclusive management and control of the spending of the money authorized to be raised through the issuance of $3 billion in bonds over the next ten years.

In his response, the California Attorney General disputed the merits of our Petition, but asked the Supreme Court to take the case, stating that: “Absent a prompt and final adjudication of the merits of this petition, the State will be unable to market the bonds pursuant to Proposition 71.”

Superior Court in Alameda County asking for a declaratory judgment that the Act is unconstitutional and for an injunction enjoining its implementation. The Attorney General filed an answer asserting a general denial of our allegations and a motion for judgment on the pleadings, set for hearing on July 14. We expect that the case will proceed in the normal manner.
The English Patient

Leslie Burke wants to live; the National Health Service has a second opinion.

London. The most important bioethics litigation in the world today involves a 45-year-old Englishman, Leslie Burke. He isn’t asking for very much. Burke has a progressive neurological disease that may one day deprive him of the ability to swallow. If that happens, Burke wants to receive food and water through a tube. Knowing that Britain’s National Health Service (NHS) ration care, Burke sued to ensure that he will not be forced to endure death by dehydration against his wishes.

Burke’s lawsuit is even more important to the future of medical ethics than was the Terri Schiavo case. Schiavo was dehydrated to death—a bitter and profound injustice—because Judge George W. Greer ruled both that Terri was in a persistent vegetative state and (based on statements she allegedly made during casual conversations some 20 years ago) that she would not want to live under such circumstances. In other words, Terri Schiavo lost her life in order to safeguard her personal autonomy, though she never made the actual decision to die.

But Burke, who is fully competent, worries that his wishes will be ignored precisely because he wants food and water even if he becomes totally paralyzed.

Burke won his case at the trial court level when a judge ruled that denying the tube-supplied food and water a patient wants “would be a breach of claimant’s rights under… the European Convention on Human Rights.” This should be uncontroversial. But the General Medical Council, the medical licensing authority, appealed, joined by the British government.

Why do Britain’s medical establishment and government insist that Burke be denied a right to decide whether he receives tube-supplied food and water? It all boils down to two concepts that are increasingly intertwined in modern bioethics theory and practice. First is the so-called quality-of-life ethic that presumes to judge the worth of patients’ lives according to their mental and physical capacities. Under this view, doctors or bioethicists may judge a life to be of such low quality that it is not worth extending, irrespective of the patient’s wishes.

The second issue is money—an especially

But Burke, who is fully competent, worries that his wishes will be ignored precisely because he wants food and water even if he becomes totally paralyzed.

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injunction taken under submission pending outcome of mediation.

Enyart et al. v. Redlands School District (Calif.)—Pro-lifers arrested on sidewalk outside high school for distributing literature and talking to students, after police officer deems this “causing a disturbance.” No criminal charges filed. Claim filed against city. Victory! Monetary settlement and expungement of arrest record.

People v. Mason (Las Vegas, Nev.)—After a day of sidewalk counseling at an abortion mill and being told by police they were not violating the law, pro-lifers were charged with trespass as they were leaving. Trial set for July 2005.

Moreno v. Riverside Community College (Calif.)—Suit against public college for arrest of pro-lifers engaged in free speech activity.

People v. Logsdon (Cincinnati, Ohio)—Clinic owner removes pro-lifer’s sign from fence and refuses to return it to its owner. When sign owner enters property and retrieves his sign, clinic owner calls police. Pro-lifer convicted of trespass. Case appealed: Victory! convictions overturned.

Logsdon v. Haines et al. (Cincinnati, Ohio)—Pro-lifer sues police and clinic for trespass of private property (taking his signs) under Ohio law.

Krug v. Billings Montana (Billings, Mont.)—Pro-life sidewalk counselors were arrested on separate occasions; all criminal charges were dismissed. False arrest suit pending.

Mason v. Colorado School of Mines (Colo.)—Following successful defense of pro-lifer for alleged trespass on public property, civil suit filed against public university for violation of constitutional rights.

Roe v. Planned Parenthood (Ohio)—Civil suit against Planned Parenthood on behalf of parents alleging that their minor daughter was coerced into an abortion by an adult boyfriend with the cooperation of Planned Parenthood employees.

(ASK THE ATTORNEY)

Jeanne Normandeau, Esq.

Jeanne Normandeau, Esq., is a sole practitioner in the Inland Empire (Riverside, San Bernardino) area of southern California, where she practices in criminal defense. She was educated at the University of San Diego, where she majored in political science, minored in international relations, and earned a paralegal certificate. She later attended Gonzaga University in Spokane, Wash., and earned her J.D. She has been practicing law in California since 1991, and has been a volunteer attorney for Life Legal Defense Foundation since 2003. She and her husband are the parents of three children. She enjoys travel and hopes to revisit her favorite place, Tahiti.

What aspect of pro-life work appeals most strongly to you?

My work is more about saving babies, though I am interested in all pro-life issues. Euthanasia bothers me but to me the most important area is abortion. Ever since I was a little kid, my mom and dad instilled within me that abortion is really wrong. Right after Roe v. Wade, when I was nine or ten, my sisters and I went with my parents on a few occasions to hold signs and protest the Supreme Court decision. My parents always talked to us about how wrong it was. We were raised Catholic and all my family still has remained very pro-life over the years.

Have you been involved in pro-life free speech cases?

One of my interests is defending the right to protest abortion. Abortion protesters don’t have the same rights to free speech as others do. Only abortion protesters have special rules and buffer zones. In no other area of free speech are there so many limitations. Speaking out against abortion is just a very unpopular stand to take.

Only abortion protesters have special rules and buffer zones. In no other area of free speech are there so many limitations. Speaking out against abortion is just a very unpopular stand to take.
said they would do some homework and would return another day if the sidewalk was in fact public property. They had intended to leave until they were asked by the Sergeant on scene to wait to discuss possible guidelines for future visits. After waiting approximately forty minutes, they were cited for trespass. The case is City of Las Vegas v. Mason and Enyart. We will be finishing up with closing arguments in July and the case is being decided by a judge because even though my clients are subjected to possible jail time for this offense, they are not entitled to a jury trial for the offense of trespass in Nevada. I am being assisted in this case by Thomas Larmore, a California and Nevada attorney.

Did a particular experience influence your decision to be more involved in pro-life work?

Two experiences come to mind. One experience involved an expectant father. When I was in the Army JAG Corps working as a legal assistant, a soldier came into my office. He was weeping. I said, “What’s wrong, soldier?” and he said, “Ma’am, my fiancée is pregnant and she is going to get an abortion tomorrow. Is there anything I can do? I want to keep our child.” I said I would see if we could get him some help, but I had to tell him that I didn’t think he had any rights. I spent more time on the phone than I should have, calling offices such as the National Right to Life and other organizations asking what could be done on his behalf. After calling as many sources as I could think of, I finally had to tell him no. We sat there and cried together. All I could think was that this child was created by both the mother and the father, and it was not right that the father had absolutely nothing to say. I vowed at that point that some day I would be involved in right-to-life work. There was one other influence. Shortly after graduating from law school, my aunt, who is also my godmother, announced, “I am so glad that we have an attorney in the family who will fight for the rights of the unborn.” I thought, “What is she talking about? I am going into the Army JAG Corps for three years.” I think it was some type of premonition because she turned out to be right, because here I am using my legal skills fighting for the rights of the unborn and defending those who try to convince mothers not to kill their babies.

How do you get your LLDF cases?

I get a call from Dana Cody, Mary Riley, or Katie Short of Life Legal. The most recent call came about Proposition 71, California’s human embryonic stem cell initiative. I am personally interested in the issue of using humans for embryonic stem cell research because one of my sisters has a “snowflake” baby, a child who was adopted as an embryo. (Snowflake children begin life when infertile couples have several embryos made during in vitro fertilization. Not all couples use all of their embryos. “Extra” embryos can be kept frozen indefinitely, destroyed, donated for research, or donated to another couple who will adopt and have the embryo placed in the woman’s womb in hopes of a successful pregnancy and birth. No two embryos are the same, hence the “snowflake” designation.) My niece’s name is Mary Elizabeth, she had her second birthday on June 15. She met the President of the United States in May when he held a meeting with families who have adopted embryonic children. There were 21 babies at the meeting, including one brand new snowflake infant, the 81st snowflake child. That 81st baby was so cute, and was pictured with President Bush on the front of all the major newspapers. I am interested in anything related to Prop. 71, including a case filed by the National Association for the Advancement of Pre-born Children. I have been assisting Mr. Martin Palmer, the attorney from Maryland that has filed this action in federal court in the Central District in Riverside this past May. My sister, Suzanne and her husband, Peter, (the mother of my niece, Mary Elizabeth) are plaintiffs in that case, which seeks to apply Constitutional protection to human embryos, who are pre-born children.

How much pro-bono work have you done for LLDF?

I have worked on about four cases for Life Legal, plus doing some other little things, like research. About twenty-five percent of my time goes for Life Legal and other Christian related litigation work.

Why do you volunteer for pro-life cases?

Because they won’t pay me! (Laughs.) Actually, I would love to do this full-time, but paid positions are difficult to come by in this line of work and I can’t afford to send our kids to Catholic school if I don’t work a paying job as well. I love volunteering for Life Legal—my reward is the satisfaction of fighting for the rights of the unborn and to hopefully, make a difference in this area of the law some day.

What would you say to a colleague who was considering volunteering?

I would tell him or her not to be a wimp—to go for it. Many people are afraid of what others will think of them about fighting for a pro-life cause. I am open about my work with Life Legal if it comes up naturally in conversation. If you think it is important to save the life of another person, go for it. Sure, everybody is busy—I am so busy, but it is so important to save the unborn.
Protect Loved Ones and Yourself from Euthanasia

In the wake of Terri Schiavo’s imposed death by dehydration and starvation, pro-life leaders are urging people to protect their own lives and the lives of their loved ones in two ways. First, by appointing an agent to make medical decisions for you in the event that you become incapable of expressing your wishes and second, by working against pro-euthanasia laws.

It used to be that there was a presumption in favor of life in the medical profession, but that has given way to a utilitarianism that places different values on human lives depending on the individual’s supposed “quality of life.” Often based upon financial considerations, hospitals throughout the country are establishing what are called “futile care” or “inappropriate care” protocols in which patients can be refused treatment even if they or their families want it. The danger now is not over-treatment, but under-treatment. Also, a federal law enacted in 1990 requires that all health care facilities which receive Medicaid or Medicare funds give every adult patient the “opportunity” to sign a Living Will upon admission.

The Dangers of Living Wills

Beware of Living Wills, even if they are promoted within your church. A Living Will can be dangerous because the focus is on the refusal of treatment. You might change your mind about what is acceptable treatment once you have been injured or become sick. For example, a person might write in a Living Will that he never wants to be put on a respirator. However, the temporary use of a respirator could save your life and help you recover if you are injured in a car accident. But if you are comatose immediately after the accident and a doctor adheres to the instructions in your Living Will, you may never get that chance to recover. In addition, medical technology changes so rapidly that Living Wills can become out of date very quickly.

The Pro-Life Alternative

Pro-life advance directives are available. These are also written documents, but the crucial difference is that you name a person to make medical decisions on your behalf should you become incapacitated. This person would be a trusted family member or friend who will be able to make good decisions based on your actual condition and the current state of medical technology. Of course, it is important to choose someone who understands your values and wishes and who is prepared to fight against hospitals and medical personnel who may feel that your life is not worth saving.

Obtaining an Advance Directive

There are different pro-life advance directives available. In contrast to most Living Wills, all pro-life alternatives state that food and water are to be provided (by feeding tube if necessary) unless death is imminent and your body is unable to assimilate nourishment at that point.

There is nothing to fear about a feeding tube; it is a simple device that has been in use for more than one hundred years. Liquid food, such as Ensure, is common and inexpensive. No one wants a feeding tube, just as no one wants dentures, but if you are hungry, you would probably be grateful to accept aid in receiving food. Sometimes a feeding tube
If you have not yet made your Advanced Medical Directive, Life Legal Defense Foundation has one suitable for California linked to its website for free download (lldf.org/pmd-inf0.html) in printable (PDF) and word-processable (RTF) formats. If you need a printed copy by postal mail, please contact the LLDF office: P.O. Box 2105, Napa, CA 94558. Please indicate how many copies you would like; a donation is always appreciated. On the same web page, there are links to alternative forms offered by other organizations, including information on how to obtain a pre-printed form from IAETF, which has forms for all U.S. states available for order by postal mail.

IN MEMORIAM JOHN PAUL II (+2005)

The gospel of life is at the heart of Jesus’ message. Lovingly received day after day by the Church, it is to be preached with dauntless fidelity as “good news” to the people of every age and culture.[1]

In fact, while the climate of widespread moral uncertainty can in some way be explained by the multiplicity and gravity of today’s social problems, and these can sometimes mitigate the subjective responsibility of individuals, it is no less true that we are confronted by an even larger reality, which can be described as a veritable structure of sin. This reality is characterized by the emergence of a culture which denies solidarity and in many cases takes the form of a veritable “culture of death”. This culture is actively fostered by powerful cultural, economic and political currents which encourage an idea of society excessively concerned with efficiency. Looking at the situation from this point of view, it is possible to speak in a certain sense of a war of the powerful against the weak: a life which would require greater acceptance, love, and care is considered useless, or held to be an intolerable burden, and is therefore rejected in one way or another. A person who, because of illness, handicap or, more simply, just by existing, compromises the well-being or life-style of those who are more favored tends to be looked upon as an enemy to be resisted or eliminated. In this way a kind of “conspiracy against life” is unleashed. This conspiracy involves not only individuals in their personal, family, or group relationships, but goes far beyond, to the point of damaging and distorting, at the international level, relations between peoples and States.[12]

The work of education cannot avoid a consideration of suffering and death. These are a part of human existence, and it is futile, not to say misleading, to try to hide them or ignore them. On the contrary, people must be helped to understand their profound mystery in all its harsh reality. Even pain and suffering have meaning and value when they are experienced in close connection with love received and given.[97]

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“...I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper purpose, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.”

—Pope John Paul II
Remembering Terri Schiavo

We want to pay our respects to Terri Schiavo and her family by continuing to remember her long after her hastened and tragic death. We also want to pay our respects by learning from this devastating situation so that others will be spared similar state-sanctioned executions and the heartbreak that attends them.

What did we learn? Was it that we better have a clear directive that provides a convincing statement of our wishes related to life-sustaining treatment? Without one, will we be at the mercy of those in our family who may want to hasten our deaths for personal reasons? If someone objects to the hastening without such a directive, will they likely find themselves and their loved one at the mercy of a judge with the judicial discretion to rule on healthcare decisions in their stead based on the testimony of other family members and “experts”?

Will such experts reason like the bio-ethicist presenting a continuing legal education course on medical ethics who responded to the following ethical dilemma as presented by an attendee, “So now here you are with a patient who has a feeding tube and you can’t get it removed.” The “ethical” response, “You want a feeding tube removed, call me. I’ll get it removed.”

Based on that example, and the cases like Terri’s that LLDF handles week in and week out, we see that the rhetoric surrounding these cases is not about the right to refuse medical treatment—it is about forcing the death of someone who needs a feeding tube because the condition that requires it has become an inconvenience for the individual in the position of substituting his judgment for the patient’s. Whether or not the patient wants the tube removed is irrelevant in today’s culture of death.

Take the recent case of U.K. citizen Leslie Burke, his case is described more completely in Wes Smith’s article in this issue of Lifeline, who is suing for the legal right to receive a feeding tube if he loses the ability to swallow. Medical authorities and the British government have appealed the trial court decision giving Mr. Burke that right, promulgating the theory that sustaining his life is a waste of precious resources. We at LLDF heard the “precious resource” mantra from those who wanted to remove Robert Wendland’s feeding tube; we hear it regularly as we intervene on behalf of patients under threat of death and we heard it in Terri Schiavo’s case.

This type of rhetoric has led our culture of death to “futile care.” Hearken back to Wesley Smith’s article in The Weekly Standard, wherein he prophetically wrote "'Futile care theory' holds that when a physician believes the quality of a patient’s life is too low to justify life-sustaining treatment, the doctor is entitled to refuse care as ‘inappropriate’—even if the treatment is wanted. It is the equivalent of a hospital putting a sign over its entrance stating, ‘We reserve the right to refuse service.’”

In its 1999–2000 Legislative Session, the California Legislature set the stage to...
implement futile care by passing the Uniform Healthcare Decision Act,\(^1\) which, among other things, delineated the duties of healthcare providers in Probate Code sections 4730, et seq. The language in sections 4730 and 4734 is especially telling in light of futile care theory:

§4730. Before implementing a health care decision made for a patient, a supervising health care provider, if possible, shall promptly communicate to the patient the decision made and the identity of the person making the decision. [emphasis added].

§4734. (a) A health care provider may decline to comply with an individual health care instruction or health care decision for reasons of conscience.

Back to the original question—what did we learn from Terri’s case? Is it that we need an advanced directive? As we read in section 4734, in California a directive may not have any influence with health care providers whatsoever. Does the meaning of “individual health care instruction or health care decision” include an advance directive?

It really isn’t clear from reading the Uniform Health Decision Act but the argument can be made that the health care provider does reserve the right to refuse service.

It may be that there is another lesson we need to learn. It was succinctly stated by Pat Anderson, formerly lead counsel for Terri’s parents, Bob and Mary Schindler. When asked if she agreed that having an advance directive for health care was the lesson to be learned from Terri’s case, she answered yes, but with one caveat: “Be careful who you marry.”

There are many lessons to be learned from Terri Schiavo’s tragic case. We think one key lesson is to take protective measures in anticipation of the eventuality of your incapacitation. We encourage our readers to implement such measures by suggesting they take great care in the following matters: 1) who you marry, 2) who you pick for your surrogate, 3) who you choose as your health care provider, and, 4) carefully document your wishes in an advance directive. If we all take these precautions, lives will be saved.

As we remember Terri Schiavo we are thankful to her and her parents for their life-saving witness. This may be of little comfort to the Schindlers after the loss of Terri, but to the extent it does give them comfort, we are grateful. May God rest Terri Schiavo’s soul.

\(^1\) Dana Cody’s interview with Janie Hickok Siess, lead attorney, In re Robert Wendland.

\(^2\) Futile Care and Its Friends: They Want to Decide Your Life is Worthless, 07/23/2001, Volume 006, Issue 42.

\(^3\) Chaptered by Secretary of State—Chapter 658, Statutes of 1999.

[Information about how to obtain recommended advance directive and protective medical decision documents is available in this issue of Lifeline.—Ed.]
(RIGHT TO KNOW CONT’D FROM PAGE 1)

the PRKCP will in one fell swoop restore some measure of authority to a significant percentage of our nation’s parents. In terms of population alone, parental notification in California will cover over thirteen per cent of our nation’s teens and parents. Because of California’s high teen pregnancy and abortion rates, the projected impact on the number of abortions and teen pregnancies is even greater. Based on the experience of other states with parental involvement laws, the state Legislative Analyst’s Office estimated that a reduction of up to 25% in the number of teen abortions in California. Although absolute numbers of teen abortions are difficult to come by, it is estimated that this 25% translates into a reduction of 5,000 to 10,000 abortions annually. As it stands now, California minors obtain as many abortions annually as in thirty other states combined.

The effect of Parents’ Right to Know would also be felt in other states. “Success with the parental notice ballot initiative in California would have a significant impact on California abortions and that, in turn, would have a positive impact on the pro-life movement across the country,” says Clarke Forsythe, Director of Americans United for Life’s Project in Law and Bioethics. “The drop in California abortions would be encouraging to the movement across the country, and success in galvanizing the public to pass the initiative in California would encourage similar efforts in other states.”

For more information about the PRKCP and how to get involved in the campaign, call (866) 828-8355 or go to www.parentsright2know.org.

Shockingly, it has been over fifteen years since any bill restricting abortion in any manner or degree has gotten out of a legislative committee.

With the Parents’ Right to Know initiative, for the first time the people will tell the legislature, the governor, and the courts what they think of the regime of unfettered abortion that has been thrust on them.

(ENGLISH PATIENT CONT’D FROM PAGE 3)

potent factor for England’s increasingly strained socialized medical system.

Accordingly, the secretary of state for health argued before the Court of Appeal that while patients have the right to refuse life-sustaining treatment, they don’t have a corresponding right to receive it. Even though the Burke case does not involve high tech medical procedures—he is not asking for a respirator or kidney dialysis, after all—the government claims that the trial court’s ruling undermines the authority of doctors to make the “clinical judgment” about whether a patient’s “treatment would be of benefit,” based at least in part on the question of “the resources which are available.” The right of doctors to exercise such control is “absolutely fundamental to the day-to-day functioning of the NHS.”

In support of the government’s position, the secretary of state filed a statement by Elizabeth Woodeson, the head of scientific development and bioethics at the Department of Health. Her testimony demonstrates the threat that contemporary bioethics poses to the lives of vulnerable patients. As Woodeson explained, the National Health Service established the National Institute for Health and Clinical Excellence (given the creepily inappropriate acronym NICE) to issue “clinical guidelines” that blend efficacy of outcomes, quality of life judgments, and economics:

An assessment is made of the cost of the treatment per additional year of life which it brings, and per quality adjusted life year (QALY)… which takes into consideration the quality of life of the patient during any additional time for which their life will be prolonged. The clinical and cost effectiveness of the treatment under review is then used as the basis for a recommendation as to whether or not… the treatment should be provided in the NHS… The Secretary of State believes that… clinicians should be able to follow NICE guidelines without being obliged to accede to patient demands.… If that principle were undermined, there would be considerable risk of inefficient use of NHS resources.

Whatever proportions these crimes [in Nazi Germany] finally assumed, it became evident to all who investigated them that they had started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basic attitudes of physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived.”

—Dr. Leo Alexander, Psychiatrist and Chief American Counsel at the Nuremberg Tribunal, “Medical Science under Dictatorship,” New England Journal of Medicine, July 4, 1949
In other words, medical care is effectively rationed by the National Health Service under guidelines set by bioethicists based on their beliefs about the low quality of life of patients whom they have never met. While the views of patients and families are to be taken into account when deciding whether to provide treatment, they are not deterministic.

This top-down approach is what Leslie Burke is rebelling against. He knows that many bioethicists have a low opinion of the quality of life of people with profound disabilities. Burke doesn’t trust doctors, much less bioethicists, to judge whether his life is worth living. “I feel strongly that my body and my being are mine,” Burke insisted when he visited him recently at his Lancaster home. “But my desire [to live] can be overridden” based on prejudice against the disabled. “I am no different than anybody else, but I am not seen that way anymore.”

Adding heft to Burke’s concerns: When I privately discussed his case with a prominent British physician who I expected would sympathize with Burke’s views, I was taken aback when he told me crossly, “Burke is only thinking of himself rather than looking at the bigger picture.” How thoughtless of him. It would be a mistake to assume that Americans are safe from having life-sustaining treatment rationed like this just because we don’t have a national health service. Burke is fighting a broader movement in the bioethics field, “Futile Care Theory,” that is becoming quietly promulgated in American hospitals. This top-down approach is what Leslie Burke is rebelling against. Burke doesn’t trust doctors, much less bioethicists, to judge whether his life is worth living. “I feel strongly that my body and my being are mine,” Burke insisted when he visited him recently at his Lancaster home. “But my desire [to live] can be overridden” based on prejudice against the disabled. “I am no different than anybody else, but I am not seen that way anymore.”

For the last several years American hospitals have been quietly promulgating futile care protocols that empower their ethics committees to authorize doctors to unilaterally refuse wanted care. These futile care policies are beginning to be imposed on unwilling patients and their families.

As is usually the case in such matters, the first victims are on the far margins. Thus, in Houston, Sun Hudson, a 5-month-old infant born with a terminal disability, was taken off a ventilator in March over his mother’s objections based on a Texas law that defers to futile care theory. Under the law, once a hospital bioethics committee determines that the treatment should not be rendered, the patient or family has a mere 10 days to transfer the patient’s care to another hospital. This can prove difficult in this era of managed care and HMOs, since the affected patients are usually the most expensive to treat. After 10 days without a transfer, the outcome is usually death following the unilateral withdrawal of treatment—as occurred in Sun Hudson’s case.

In another Houston case, one with ironic echoes of Terri Schiavo, the wife of Spiro Nikolouzos wants tube-feeding for her persistently unconscious husband, based on his previously stated desire to live. But unlike Schiavo’s, Nikolouzos’s personal wishes are not deemed determinative: A hospital ethics committee voted to refuse to continue his tube-supplied food and water and ventilator support. He would have died, but a San Antonio hospital unexpectedly agreed to provide the care. Then its ethics committee also decided to cut off care, but Nikolouzos was transferred to a nursing home. For the moment, Nikolouzos is being allowed to stay alive. But the final decision about the matter isn’t his wife’s: Under futilitarian Texas law, it belongs to committees of bioethicists and doctors.

In this darkening atmosphere, the Leslie Burke case could not be more important. If Burke loses on appeal, patients in Britain will be stripped of the basic human right to receive food and water through a feeding tube.

Moreover, given the increasing propensity of some Supreme Court justices to look overseas when deciding issues of American law, a Burke loss could plausibly end up reinforcing futile care laws in this country. There will undoubtedly be protracted litigation on this issue in coming years. How Leslie Burke fares will be stripped of the basic human right to receive food and water through a feeding tube. Such a ruling should send a cold shiver through disabled, elderly, and dying patients everywhere.

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Moreover, given the increasing propensity of some Supreme Court justices to look overseas when deciding issues of American law, a Burke loss could plausibly end up reinforcing futile care laws in this country. There will undoubtedly be protracted litigation on this issue in coming years. How Leslie Burke fares may determine whether futile care theory is allowed to metamorphose from ad hoc health care rationing into an explicit—and expanding—duty to die.

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[This article was originally published May 30, 2005 by The Weekly Standard and is here reprinted by the kind permission of the author. Wesley J. Smith is a senior fellow at the Discovery Institute (discovery.org), an attorney for the International Task Force on Euthanasia and Assisted Suicide, and a special consultant to the Center for Bioethics and Culture (thebcs.org). He is the author most recently of Consumer’s Guide to a Brave New World.]
LLDF Banquet Announcement

Mary and Bob Schindler, parents of Terri Schiavo, will be speaking at Life Legal’s annual Fall banquet. This will present an opportunity to hear the Schindlers present their first-person account of their loss of Terri and the long and difficult legal struggle beforehand to provide her with therapeutic medical care and finally and unsuccessfully to prevent her being starved to death at the mercy of the courts. How this series of events started and ultimately could not be stopped, even with a national effort, is of tremendous value in terms of public education and working to establish moral and humane legal guidelines for end of life care.

The banquet is scheduled for 5:00 p.m. (dinner at 6:00), Saturday, November 12. The banquet will be held at the Berkeley City Club (2315 Durant Avenue, Berkeley, near the southwest corner of U.C.). Berkeley City Club is a beautiful site of historical note, it was designed and built in 1929 by Julia Morgan (of Hearst Castle fame) and is now a California state landmark. We at Life Legal will look forward to seeing you there.