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## President's Page

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## President's Page

### *Phillip Becker and the Right to Privacy*

If *Screwtape*<sup>1</sup> were writing letters in the 1970's, he might well boast of the diabolical discovery of a constitutional "right to privacy." Beginning with *Griswold vs. Connecticut*, which has led to the virtual displacement of parents by Planned Parenthood social engineers in the influencing of adolescent sexual mores, the "right" which was undiscovered for almost two centuries has been carried to incredible extremes by the Burger court. The right of privacy in abortion decision-making has been carried far beyond the original excesses of *Roe vs. Wade* and *Doe vs. Bolton*. Not only have parents lost their right to participate in their children's decision-making, but husbands have lost the privilege of influencing their own child's possibility of survival, health departments have lost their right to regulate the performance of abortion, and, if the Dooling decision is sustained, Congress will have lost its right to disburse funds for abortion through the Hyde Amendment.

Another locus for the "right to privacy" has been expounded by the New Jersey Supreme Court in the Karen Quinlan case — the right to privacy in refusing treatment. While no one would want to deny any competent patient the right to refuse extraordinary care, the precedent established by the Quinlan decision has some profoundly disturbing implications for proxy consent. No one questions the sincerity or the good motivation of the Quinlan family, however the decision of the New Jersey Supreme Court transcends the circumstances of the Quinlan case. In effect, the court states that next of kin

may exercise for incompetent patients a "constitutional right to privacy." The danger of this solution is that it disenfranchises the attending physician in those situations where the decision of the next of kin may be lethal to the patient and where the medical treatment recommended is neither extraordinary nor futile. This poses a formidable obstacle for any attending physician who may wish to retain control over circumstances where near relatives may "want the patient dead for the wrong reasons."<sup>2</sup> The famous Johns Hopkins case in which surgery was denied for duodenal atresia *because* the patient had Down's Syndrome is paradigmatic of this kind of situation.<sup>3</sup> In reaching its decision, the Supreme Court of New Jersey did not say that the attending physicians in the Quinlan case were wrong in applying the standards of good medical practice. It did not even say that the lower court was wrong in sustaining the physicians in their action. The Court merely asserts that it will not be "bound or controlled" by medical standards in intervening on behalf of a right to privacy. This judicial tyranny is carried a step further by the Massachusetts Supreme Judicial Council in the Saikewicz case. In that decision the court said that proxy decision-making for every incompetent in the state belonged exclusively to the court and "that responsibility is not to be entrusted to any other group purporting to represent the 'morality and conscience of our society,' no matter how highly motivated or impressively constituted." This decision now attempts to move life-and-death decision-making away from family, physicians, or guardians and to locate it as a matter of what amounts to judicial privacy. Here again, the issue is not whether the court was or was not correct in recommending that Saikewicz (who was a 67 year old Down's Syndrome patient in Belchertown State Hospital) should not receive chemotherapy for leukemia. In reaching that conclusion, the court was either wrong or right for the wrong reasons.

It is perhaps too facile to see a logical progression from the Johns Hopkins case to the New Jersey Supreme Court decision to the position of the Massachusetts Supreme Judicial Council. All involved proxy consent for incompetents and all involved serious implications for the role of the physician in such decision-making. It is not merely paranoid to see an erosion of the physician's contribution nor is it sufficient to point out that, in some instances, the physician has freely abdicated his role to the court. This issue arises again in the Phillip Becker case.

The case of Phillip Becker in California raises questions of great poignancy. The medical facts are very difficult to weigh and both the medical testimony and the judicial opinions raise profoundly disturbing questions. At issue was the question of whether Phillip, a 12 year old Down's Syndrome child, should have cardiac surgery for an intraventricular septal defect. Since surgery had been delayed, the child had developed pulmonary hypertension creating an expected

mortality of about 5% for the procedure. The pediatric cardiologist, in recommending the procedure, pointed out that Phillip was unusually bright for a child with Down's Syndrome "falling into the top 5-10% of such children in terms of educational potential." Phillip was described as being able to feed and dress himself, fold laundry, feed the cat, and make his bed. Without the surgery, he could be expected to deteriorate in adolescence and to die by the third decade of life.

Although the indication for surgery cannot be said to be incontrovertible, the reasons presented in court for withholding surgery were most unfortunate. A pediatrician (who was himself the father of a retarded child) stated that he did not feel the surgery should be done "with the goal of increasing the life expectancy of a life that I consider devoid of those qualities that give it human dignity." The similarity of language to that of early theorists of the Third Reich<sup>4</sup> is particularly unfortunate. Phillip's father, who emerges from the transcript as a most anguished parent, testified under questioning that he thought his son would be "better off dead than alive." His reason for this conclusion was his fear that the child would be consigned to a "warehouse institution" after his parents had died and were unable to provide for quality care. This presumption of low standards of care for the indigent retarded would be a very tragic element to be accepted where life and death decisions were being made for the handicapped. Facilities for the care of the retarded have only recently emerged from the bedlam-like standards of the 1940's and 1950's and it would be regressive if a court were to accept as a "given," the notion that the choice for institutionalized mental defectives is either death or life under deplorable conditions.

A petition to make Phillip a ward of the Juvenile Court for the purpose of giving consent for the surgery was denied by Juvenile Court Judge Eugene Premo. In oral remarks, he cited nearly plenary rights of parents in denying consent. It would appear that Judge Premo, in reaching his decision, had required a higher standard of proof of the need for surgery than what would have been applied to a situation involving a juvenile of normal intelligence. The judge ruled that there was not "clear and convincing" evidence that the surgery was needed and that the child would survive and benefit from the operation. Attorneys for the California Pro-Life Council pointed out that the usual standard used in such cases involving juveniles was proof by "preponderance of the evidence." A California appeals court, however, ruled that the correct standard of proof had been used and that the 5-10% risk of mortality was an "unreasonable" one.

It would be most unfortunate if this case should become a precedent for a double standard of proof. If it is concluded that a normal person is allowed to take a higher risk than a handicapped child or adult in a similar situation, then not only Phillip Becker but a whole class of citizens have had their rights eroded.

The recurrence of cases involving patients with Down's syndrome is symptomatic of the diminished citizenship of such persons whether at Johns Hopkins, in Belchertown, or in California in the case of Phillip Becker. Some authors have described terms such as "sanctity of life" or "worth of every individual" as "talismanic incantations" which interfere with analysis and enlightenment. If we prescind from such judgments, however, we are left with the unbelievably tortured circumlocution of those who have prejudged the quality of life of the child or adult with Down's Syndrome. Killing the child with Down's Syndrome *in utero*, after viability but before birth, becomes the "prevention" of Down's Syndrome in medical parlance. If we decide that the Down's Syndrome patient should not survive because of his intellectual limitations, then therapy becomes his enemy and any potentially fatal disease becomes his friend. This is obvious in the commentary on Saikewicz in particular. We are told, for example,<sup>5</sup> that if his "leukemia is left undisturbed, Saikewicz will die relatively quickly without pain or discomfort." When one reads such a statement, it is questionable why we would ever want to treat any patient with leukemia. Without belittling the complications of therapy, no one who has spent any time on a busy hematology-oncology service would ever describe death from leukemia in such sanguine, sugar-coated terms. There are situations incontrovertibly where irrational vitalism has led to the use of toxic modes of therapy in a manner which merely prolongs and exacerbates the dying process. These situations are the same for the patient with Down's Syndrome as in the normal patient. It is fair to say that Joseph Saikewicz could "understand" his therapy as well as any two year old leukemic of normal intelligence and probably "cooperate" as well in the carrying out of the therapy (that is to say, to resist and react to all that is painful). If we decide to withhold therapy for Joseph Saikewicz, it is because he is like any other old man for whom a transient remission is of questionable risk/benefit indication. Similarly, the decision for surgery on Phillip Becker should not be qualified by a suspicion that the society will not do right by him if he happens to outlive his father. Phillip Becker will be denied equal access to medical care unless his life is "sacred" and possessed of irreducible value.

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