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Update

Faith, Medicine, and Religious Liberty

Part II
Christian Science

Spiritual Healing For Children

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Should medical care be mandatory for all children? No. I hope to show this is a reasonable position not based solely on the argument of religious liberty—as essential as that is—but also on the volume of experience attesting the efficacy of spiritual healing in Christian Science.

For over a century, Christian Scientists have quietly relied on spiritual means for healing. Respectful of others' rights of conscience and enjoined not to proselytize, they seek to exemplify the sentiment of Mary Baker Eddy, the founder of Christian Science. "Our Master's injunction is that we pray in secret and let our lives attest our sincerity." (*Science and Health with Key to the Scriptures*, the companion book to the Bible for Christian Scientists). In weekly church services throughout the world, people share healings they have experienced through prayer alone. Verified testimonies appear in all the church's religious magazines. Over 50,000 such healings have been published to date, but this is by no means an exhaustive compilation. Prominent among these healings are those of children. When I was growing up in a family of six active children, all of our diseases and injuries, as well as our personal and emotional problems, were healed exclusively through prayer. Through Christian Science treatment alone, my sister's broken arm was set and mended the same day. A relative immediately took her to a doctor, who, looking at the X rays, wanted to know how many weeks it had been since the break. He added, "It's the neatest setting of a bone I've ever seen."

Unaware of the frequent occurrence of such healing or unwilling to objectively consider it, some people feel that spiritual healing must be submitted to controlled medical testing before it can be considered legitimate. But the fact that the very nature of spiritual healing does not lend itself to such testing cannot justify dismissing the evidence of this healing found in so many people's lives,—healing that so often includes great moral and spiritual regeneration (which is difficult to examine in a test tube). Interestingly enough, significant medical verification of such healing (if not controlled testing) does exist. For example, *Spiritual Healing in a Scientific Age* by Robert Peel (Harper & Row, 1987) records dramatic recent Christian Science healings—many of children—that were medically documented. Also, in a study of testimonies of physicial healings published in Christian Science periodicals during a recent 20-year period, nearly a quarter of the healings were of conditions that were medically diagnosed. ("An Empirical Analysis of Medical Evidence in Christian Science Testimonies of Healing, 1969-1988," *Freedom and Responsibility: Christian Science Healing for Children*, The First Church of Christ Science, Boston, 1989). For someone who has not experienced or witnessed such healing first-hand, the difficulty of believing these accounts is understandable. But if a genuine spiritual healing is simply discounted or ignored, that is a loss to society's growing understanding about the very nature of healing itself.

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on
Baby Theresa

The public often assumes that Christian Scientists ignore physical problems. Not true. We conscientiously report and quarantine contagious diseases, and cooperate with public health authorities. We, too, are concerned when someone is sick or injured and we take practical steps to meet the person's needs. Although our approach is nonmedical, we heal physical needs through what we believe is the method taught and practiced by Christ Jesus and his disciples. As to why we do not combine prayer with medical treatment, we have found that mixing Christian Science treatment with medical treatment is almost always unsuccessful; that the fundamental teachings of the two systems about the nature of man and the source of health generally contradict and work against each other.

In a life-long search for a more spiritual understanding of God and of Christ Jesus' teachings, Mrs. Eddy became convinced that pure Christianity is as practical and viable in meeting our human needs today as it was in the Early Church. She explained "miracles" in the Bible as the natural effects of God's law governing all creation (which Jesus understood and obeyed) rather than as miraculous suspensions or interruptions of universal laws of matter. She considered her discovery to be deeply Christian, and was confident it would have a significant role to play in the medical dialogue about how healing occurs, especially in terms of the effect of thought on the body and the scientific nature of Jesus' healing practice.

There has been a long tradition in the U.S. of legal accommodation for responsible spiritual healing on both the state and federal level out of respect for religious liberty and because of Christian Scientists' reputation as conscientious, law-abiding citizens. (See Tom C. Johnsen, "Christian Scientists and the Medical Profession: A Historical Perspective," *Medical Heritage*, Jan/Feb 1986). This whole tradition is now threatened by current court cases. Increasingly Christian Science is judged on the basis of a relatively few tragic failures, while ignoring its overall record of healing—a standard usually not applied to medical practice. A century of extensive Christian Science healing is often dismissed largely because it does not conform to current theories and practices of conventional medicine.

"The duty of our society to protect the wellbeing of its children is paramount"

Most Christian Science children are growing up in moral, Christian homes free of alcohol and drugs. They are being raised by loving parents who care deeply for their physicial and spiritual needs. And they are experiencing healing through spiritual means. I sincerely pray that the public recognition of the efficacy of Christian Science which has stood for more than a half century not be precipitously overturned; that children and their families never be prevented from turning to a method of worship that heals, merely because society has had difficulty judging it objectively. The duty of our society to protect the wellbeing of its children is paramount, but it should not supersede religious liberty where there is a responsible spiritual approach to healing. ■

Religious Liberty, Spiritual Healing, and the Health Care of Children

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This discussion centers in three major areas: religious liberty, spiritual healing and the health care of children. I will address the third area with as much balance and equilibrium as I can.

Spiritual healing is something I also have experienced. It is not something distant or incredible to this practitioner of the medical arts. Ambrose Pare, a French military surgeon, once said, "I treat, God heals." This motto has become more impressive for me than the Hippocratic Oath (which the students of Loma Linda University School of Medicine do not take, contrary to what many suppose). Most health care and restoration of health involves the co-working of the intellectual, the mechanical and the spiritual. With several of my patients I have been inspired and amazed by the intervening healing power of God. I wish I could tell you that all of the subjects of prayer and parental desire gained health and restoration. They didn't. Some died in spite of the fervent prayers and dedication of the parents and staff.

I remember a situation in which I had to intervene to restrain the professional efforts of the nursing and medical staff. They felt the parents were absurdly insisting upon delays for prayer. In this case I put my profession on the line and I prayed with the parents, though their prayers ascended to heaven for what seemed to be an impossible situation.

This case of a little girl with inoperable heart disease who had developed severe infections, profound brain hemorrhage, and hyhdrocephalus seemed truly hopeless. We felt there was little left to offer her. The parents continued to insist upon divine intervention and prayer. They asked us to refrain from doing some of the things we planned to do.

We cooperated, and we lost the little girl—not to death but to our follow-ups. Soon afterward she was able to leave the hospital, though still an invalid. We did not see her for quite some time. My face was wet with tears when I saw her ten years later. She was not a fragile, cyanotic girl, but a robust young woman who ran up to me, embraced me, and called me by name, and gave me a big hug.

This was outstanding evidence that spiritual healing plays a part, along with the medical community, in intervening. Our medical principles, as laid down in expensive textbooks, are not the only concepts by which we can seek the health care of children.

As to our intervention with the health care of children, my heritage certainly is one of very strong parent-child involvement. My family would consider it anathema to

remove a child from its parent's custody, and I don't think I could withstand such a trauma. However, in my current professional role, daily I have to order drug screening tests on children, search medically for sexually-transmitted diseases in newborn infants, and often ask the authorities to restrain parent-child contact and bonding.

It's a sad milieu in which we practice medicine. To defend absolute parental rights to decide the health care of their children without authoritative restraint would be absurd in a society with drug use, sexually-transmitted disease, and even satanistic rituals that include child sacrifice. One can easily cite examples of bizarre and destructive treatment of children to show that parental rights are not absolute. To stretch this into precise medical and health-care decisions such as chemotherapy versus nutritional therapy, blood transfusions versus intravenous substitutes for blood, or surgery versus prayerful delay, is to deal with the dilemmas facing biotechnology today.

However, I previously cited situations where the absolute authority exercised by medical professionals over a child's care could also be wrong, and where the spiritual concepts, allowed to manifest themselves, could produce a healthful situation for the child.

The presupposition that life is to be preferred over death is embodied in our common law. The ethical principle of acting "in the best interest" of the minor is the justification for using life-preserving interventions and life-saving methods even when it contradicts or violates parental religious beliefs. But for some, life has become a worshipful object in itself. For others the worship of a Creator who gives life and has restorative and redemptive powers is the object of our respect.

At a Harvard-sponsored ethics conference in 1988, I submitted this question: Is not the patient's belief about life after death a necessary consideration when making an ethical life-and-death decision? I hoped they would consider that. They didn't. It was rejected without response. It's not a popular question in scholarly societies, but I hope we'll continue to bring this question before our professional peers.

Ethics committees, in dealing with the preservation of fragile human life, have found many exceptions to the conviction that preserving life at all costs is always in the best interest of the patient, the family, or society. These costs may include financial, emotional and physical pain. The absolutist may proclaim that life above all is to be preserved, but that absolutist may not have been in the same trenches I've been in when dealing with children whose actual flesh was rotting from their bodies, whose brains were so destroyed that there was no possible concept of survival. Our previous concepts of preserving life have been modified by our technological milieu in which we can sometimes maintain a heartbeat and respiratory effort without preserving life as we previously knew it.

Patients often ask the State or medical authorities to pause for prayerful intervention for God's will. As one father of a patient of mine in Tennessee so eloquently expressed it, "Get out of the Man's way and let him do his thing." To insist on the continuation of high-tech rituals with no chance for human success is as absurd as some of the religious rituals at which our intellectual society laughs.

I offer a metaphor: It would be such a relief from the white water torrent of decision-making in which we are being swept to crawl out on the bank of the State's knowledge of legal rightness or moral certainty. It would be equally comfortable to swim to the opposite shore of free human decision-making without the restraint of supervision or authority. But I suggest that we are destined to stay in the middle of that stream, to keep on paddling, and to try our best to miss the big rocks.

It would be highly desirable if a medical setting would be made available to all grieving and concerned parents where their religious beliefs and rights would be duly respected. These convictions should be given full consideration while negotiations for a legally and ethically appropriate course of action in behalf of the child that is loved continues. ■

Spiritual Healing, Laws, and Constitutional Free Exercise of Religious Rights

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Laurie Grouard Walker, a 30-year-old Christian Scientist mother, consistent with her religion, utilized a church practitioner nurse to treat Shauntay with prayer and frequent visits. She lost her four-year-old son to purulent meningitis sixteen days after she noticed flu-like symptoms.

Her conviction on involuntary manslaughter and felony child endangerment was appealed. Earlier, the Supreme Court concluded Walker could be charged on those two counts, virtually tying the jury's hands.

The California Supreme Court rejected the premise that California's penal code, Section 270, was intended to protect parents from criminal charges. The code states that if parents of a minor child willfully omit furnishing necessary clothing, food, shelter, medical attendance or remedial care they will be guilty of a misdemeanor punishable by a fine or imprisonment.

The court pursued a tortuous effort to prove that remedial care is not an acceptable substitute for medical attendance. The code states, "If a parent provides a minor with treatment by spiritual means, through prayer alone, in accordance with the tenets and practices of a recognized church or religious denomination by a duly elected practitioner thereof, such treatment shall constitute 'other remedial care,' as used in this section."

The amendment was added to protect Christian Scientists from criminal charges when spiritual healing failed to heal.

Remedial care through prayer has nothing to do with clothing, food, or shelter, whereas illnesses have been resolved without medical attendance. Still grieving her loss, Walker faces a prison term for conscientiously following her religious belief, which is protected by a clear and plain reading of the law.

A Boston, Massachusetts judge recently found David and Ginger Twitchel, Christian Scientists, guilty of involuntary manslaughter for not seeking conventional medical care for their son, Robyn, who developed varying flu-like symptoms and died with a bowel obstruction due to a rare congenital birth defect.

Judge Sandra Hamlin, with the jury out, refused to allow as admissible a 1971 amendment to Massachusetts law, which provided parents with an exemption from criminal liability in the event that they used spiritual healing to treat their children. The jury, unaware of the amendment, could not render a fair verdict.

Courts are misinterpreting the Constitution, violating the plain language of the law, and blatantly refusing to inform the juries of legal provisions. It was precisely to avoid such conflicts that the First Amendment to the Constitution was written. "Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof."

The U.S. Supreme Court, in W*atson v. Jones* (1872) declared, "The law knows no heresy, and is committed to the support of no dogma, the establishment of no sect. The Founding Fathers intended that the constitutional rights, whether civil or religious, were not to be conditioned upon the social acceptance or majority opinions of society."[1]

Leo Pfeffer, noted constitutional expert, wrote, "The smaller the minority, the more likely it is to need constitutional protection."[2]

It took a century before the U.S. Supreme Court first restricted the free exercise of religion. *Reynolds v. United States* (1879) ruled that because marriage was a "sacred obligation," the Church of Jesus Christ of Latter-day Saints could not practice polygamy.[3] Today, such a conclusion would be nearly impossible in light of social customs. Free exercise was significantly circumscribed—permanently. The court declared, "Laws are made for the government of actions, and while they cannot interfere with mere religious belief and opinions, they may with practices."[4] The government seems willing to apply a double standard, denying practices for religious reasons, while approving socially acceptable ones.

Amish parents, criminally indicted for refusing to send their children to public school after they reached the age of 16, were cleared. *Wisconsin v. Yoder* (1972) held that, "only those interests of the highest order and those not otherwise served can overbalance a legitimate claim to the free exercise of religon."[5] In civil and criminal instances, general laws have waived penalties because of compelling free exercise rights.

The American Academy of Pediatrics, in 1988, called on forty-five states to remove spiritual healing exemptions, making criminal what has not been criminal.[6]

Following The Civil Rights Act of 1968, and its 1974 Title VII amendment requiring reasonable religious accomodation, the Department of Health, Education and Welfare ordered states to write religious exemption statutes for spiritual healing into child abuse laws, or risk losing federal funds. About ten years later, the department dropped the requirement, but most of the states retained the exemption.[7] The Reagan Administration's lack of support for civil and religious rights began the fragmenting of those freedoms.

Virtually all children receiving Christian Science spiritual healing who died were diagnosed in the early stages as having flu-like symptoms. Death followed sudden complications—usually from meningitis or lung infection. Even physicians cannot always accurately detect the seriousness of certain critical diseases at their onset.

This was brought dramatically to the entire nation when Muppets creator, Jim Hensen, was examined and the physician thought he had flu. In a few days Henson died. The *Los Angeles Times* ran articles on Los Angeles-area hospital death rates, concluding that about 6 percent of the heart patients died in surgery. Very rarely is a physician charged with malpractice or a civil suit when his patient dies from surgery, misdiagnosis, or inadequate treatment. Criminal charges are almost unheard of.

The issue must be faced squarely. The medical profession cannot provide optimum treatment to all patients, so a percentage die prematurely. Is it not understandable that a layman, following his religious belief, may misdiagnose the child's illness, that a faith practitioner may not sense the critical condition, and on occasion a child will die?

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The state is empowered as *parens patriae* to step in when the child is not being cared for. If the state oversteps its role to save child, or a parent, from his or her religion, that state will influence, if not determine, the religious future of that family and ultimately of the nation.

The framers of the Constitution specifically used "exercise," for they wanted actions protected. That created a constitutional right to religious freedom. More recently, courts have created a right of the state to serve as *parens patriae.* Clearly the question is, where should the line be drawn?

Since Congress adopted religious accommodation statutory provisions, and since state laws make it possible for people to follow their faith without being charged with criminal negligence, it would seem that the line should be drawn allowing parents to follow sincere religious belief. They should not be brought to criminal trial because a child has died.

> *"The state is empowered as* parens patriae *to step in when the child is not being cared for."*

The most devoted followers of faiths are not willing to knowingly make martyrs of their children anymore than physicians. Yet children die, and so do adults—from both kinds of treatments.

The picture is not that clear that parents holding religious beliefs precluding normal medical treatment are wrong, and the medical profession is right. Many believe the medical profession has much to offer to parents with sick children. But then, they cannot exercise someone else's faith, nor can they serve as another's conscience. Criminalizing good-faith participation on the part of a religious adherent in following spiritual healing should not be criminalized, whether there is a state or federal statute calling for exemption or not, because the Constitution protects their free exercise.

A concerned party, aware of the child's deteriorating illness, could report the incident to the proper law enforcement agency. A hearing could receive a medical diagnosis and recommendation as well as those of the church practitioner. A judge, knowledgeable in constitutional rights and medicine, would make an appropriate decision. If the court deemed it necessary to turn to conventional medicine, it would appoint a guardian *ad litem.* The child would receive conventional treatment and, assuming recovery, be returned to the parents. Recovery from sickness cannot be guaranteed either by religion or the medical profession. Being human, all have their shortcomings.

Many Christians believe in spiritual healing. Most accept prayer and the anointing healing. "Pure air, sunlight, abstemiousness, rest, exercise, proper diet, and use of water, trust in divine power—these are the true remedies."[8] Most admit that natural remedies are basic to healing. But such remedies take longer than drugs and are more difficult to administer because of the personal discipline that is required.

Spiritual healing is a relatively popular teaching in most religions, even though the interpretation of how to apply the spiritual healing differs from denomination to denomination, and even from person to person.

Does the established community of medicine have the right to deny religious freedom to parents who are honestly and sincerely attending their children's illnesses? If medicine succeeds in denying those constitutional rights through the judiciary and legislatures, then other Bill of Rights freedoms will be imperiled, including its own professional practice.

There is a serious need for the medical profession to more fully understand the free exercise problem. There is also a need for those who use spiritual healing to understand that when a child is ill and begins to deteriorate rapidly, seeking medical help might save a life.

Perhaps the balance being sought was epitomized in the life of Norman Cousins, who wrote, "For the founders had a deep respect for the spiritual urge in man. If man's natural right to his religious beliefs was to be upheld, he had to be protected, not only against the authoritarian, anti-religious state, but against religious monopoly."

Cousins, highly respected in medical circles, exemplified the values of the spirit of healing, cheerfully laughing his way to health, encouraging people to have positive attitudes in order to overcome illnesses. Several of his books on the subject became bestsellers.

It is vital for the medical profession, constitutional scholars, and religious leaders to resolve these mounting problems and come to a satisfactory solution, giving respect to all differing viewpoints. If they don't, a growing government will, and in the end all could end up losers.

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[1] *Religion an the State*, James E. Wood, Jr., Editor, Baylor University Press, Waco, Texas, 1985. p. 193.

[2] *Church State and Freedom*, Leo Pfeffer, Beacon Press, Boston, Massachusetts, 1953, p. 616.

[3] *Toward Benevolent Neutrality*, Robert R. Miller, Ronald B. Flowers, editors, Markham Press Fund, Waco, Texas, 1982, p. 70.

[4] *Religious Freedom*, Leo Pfeffer, National Textbook Company, Skokie, Illinois, 1976, p. 33.

[5] *God, Caesar, and the Constitution*, Leo Pfeffer, Beacon Press, Boston, Massachusetts, 1975, p. 35.

[6] "Prescription for Controversy," Rob Boston, *Church and State*, March 1989, Silver Spring, Maryland, p. 9.

[7] *Ibid.*, p . 12.

[8] *Los Angeles Times*, Los Angeles, California, "Surgical Mortality Rates in California Hospitals," March 27, 1988.

[9] *Ministry of Healing*, Ellen G. White, Pacific Press, Mountain View, California, 1942, p. 127.

[10] *Classics of Religious Liberty*, Albert J. Menendez, Americans United Research Foundation, 1978, "In God We Trust: The Religious Beliefs and Ideas of the American Founding Fathers," Norman Cousins, p. 52. ■

Baby Theresa:
Parental Choice Must Reign in the Case of Brain-Absent Newborns

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When a baby such as Theresa Ann Campo Pearson is born with only a rudimentary brain stem and faces imminent death, why can't her parents choose to donate her vital organs so that another baby might live? There's a simple answer: It's against the law. The law, in all 50 states stipulating the necessity of the death of the *whole* brain, of course, can be changed. But the question is whether such change would be good.

There are at least four different answers to whether an alteration of law would be appropriate:

Philosophical acceptance. An anencephalic newborn is, unfortunately, an infant whose diagnosis is incompatible with life. Because the newborn does not and will never possess cerebral spheres or a neocortex, it has no possibility of becoming a person in any way analogous to the reader of this page. Hence, the anencephalic infant does not possess the moral status of a normal newborn. Baby Theresa Ann "has more in common with a fish than a person," says physician-bioethicist Robert Levine of Yale University, as quoted in a recent *New York Times* story (March 29, 1992; p. 10). "Our brain stems do not differ substantially from the brain stem of a fish."

Theological objection. God created human life in his own image, and that life is sacred. Some theologians emphasize the importance of embodiment. It is acknowledged that anencephlic infants have no cognitive ability, but they are viewed as embodied persons, albeit with a severe abnormality. Embodiment theology contends that an unfortunate dualism is held by those who fail to reverence an embodied individual who happens to possess a partial brian. Other theologians are convinced that ensoulment is the basic issue. That is, every human being regardless of age, stage of development or cognitive status possesses an immaterial soul. A basic human spirit or soul is possessed by every member of the species *Homo sapiens* and thus every human has moral worth. Although these views are rationally developed by certain theologically conservative thinkers, many with roots in the Roman Catholic tradition, a vitalistic ethos is widespread throughout the population.

Pragmatic reluctance. Some bioethicists believe it is intrinsically moral to use anencephalic infants as organ sources, but are reluctant for extrinsic reasons. There are millions of Americans who now do not sign organ donor cards, and apparently it is because of fear that the medical establishment can't be trusted. Some fear a premature determination of death in their personal cases may be made for transplantation reasons. Because the whole system of organ donation is voluntary, public confidence must not be shaken by the controversial use of organs from newborns who are questionably dead.

Visceral repugnance. This fourth camp may have some application to knowledgeable specialists, but it is more directly applicable to society at large. Typically, many specialists who are in the first or third groups feel that society is not ready to accept use of anencaphalic infants as organ sources. If infants like Baby Theresa Ann were used as organ sources, society would have to redefine death as death of the cerebral hemisphere, and I don't think society is ready to do that," recently stated Les Olson, director of organ procurement for the University of Miami (*Los Angeles Times*, March 28, 1992, p. A22). Olson may be right. The brain stems of anencephalic infants allow for many typical newborn activities. In addition to circulatory and respiratory functions, crying, swallowing, and regurgitation occur. Newborns with incomplete anencephaly may have the mobility of a four-month fetus, and all anencephalic infants respond to vestibular stimuli and some to sound. Reflexes are usually strong, particularly the response to painful stimuli. The grasp reflex is easily initiated. (See Kenneth R. Swaiman and Francis S. Wright, *The Practice of Pediatric Neurology*, Vol 1, St. Louis: The C. V. Mosby Company, 1982, p. 410).

Organ procurement from anencephalic infants is controversial. If the anti-abortion contingent can make a fetus yield a "silent scream," think of the torrent of words which could be coaxed from a knit-capped anencephalic newborn! A surgeon could reply that bodily movement from a higher brain-absent newborn is not totally different from the reflexive movement at times displayed by a dead subject just prior to organ procurement. The surgeon trusts the brain-death determination of the neurologist, not the presence or absence of certain spinally-induced movements.

Because anencephalic organ procurement is so controversial, society has several options: first, we can do nothing; second, we can change the law from whole brain death to cerebral death; third, we can allow parents to choose among circumscribed options.

Precisely because society is so divided over the moral status of anencephalic infants, parents should be able to choose among three definitions of death for their anencephalic newborns: a) cardio-respiratory death: cessation of heart and lung functioning, b) whole brain death: cessation of the total brain activity, including the brain stem, or c) cerebral death: absence of higher brain functioning.

Who would choose which options? Some orthodox Jewish parents may opt for the traditional cardio-respiratory standard. Many parents would accept society's current definition of death, whole brain death, as applicable to their newborn. Other parents, those who view possession of higher brain functioning as that which bestows upon an individual a unique claim to existence, would choose cerebral death and

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Anencephalic Infants as Organ Donors: Do We Follow Rules or Emotions?

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The judges in Florida who heard the request of Baby Theresa's parents to declare her dead had no choice but to deny the request. The rules are clear. The Uniform Antomical Gift Act (UAGA) says that vital organs may be harvested only from dead bodies. The Uniform Determination of Death Act (UDDA) says that bodies are dead when there is irrreversible cessation of respiration and circulation or irreversible cessation of function of the entire brain. Live-born babies with anencephaly like Baby Theresa do not meet the criteria for death; therefore, vital organs may not be harvested from them.

But the utilitarian argument for the use of organs from these babies has strong emotional appeal. Isn't there some way we can reap some benefit from this tragedy and help other doomed infants? The only options are to follow the rules, ignore the rules or change the rules.

The neonatal and transplant teams at Loma Linda were the first to make a concerted systematic effort to harvest organs from babies with anencephaly by following the rules. The results were very disappointing and were not productive of usable organs. Following the rules does not work. It is very doubtful if any medical team or judge will be willing to repeatedly, or even occasionally, ignore these serious and important societal rules. Thus, the only way to salvage these organs is to change the rules.

We could change the UAGA to allow removal of organs from bodies before they are dead. This idea is unlikely to gain support, and its implementation would seriously decrease the already limited number of willing organ donors. We could change the UAGA to allow removal of organs from dead bodies and newborns with anencephaly as a unique situation. We could change the UDDA to allow less rigid criteria for the declaration of death. There have been three serious proposals in this regard. An Ohio bill to allow declaration of death using only apnea as sufficient evidence of brain stem dysfunction was not passed and the proposal has not received support from the medical community.

A second proposed change to the UDDA by Robert Truog and John Fletcher was to redefine death as the absence of integrative brain function such that somataic death is imminent. They believe that only people who are brain dead or have anencephaly meet these criteria. This is another way to say that infants with anencephaly are unique. More about that later.

The third proposal to change the UDDA is to use death of the neocortex instead of death of the entire brain. There is considerable support for this change in both the medical and philosophical communities since it is the upper brain (neocortex) where individuals think and feel and have their awareness. Implementation of this definition would mean that thousands of individuals in this country who are alive today and have adequate spontaneous respiration and circulation would suddenly be reclassified as dead. Organs may be removed from dead people, and dead people may be buried. This definition of death does not seem workable because of imprecision and aesthetic abhorrence. Absence of neocortical function leaves a person in a persistent vegetative state, and there is considerable difference of opinion about the criteria for this clinical diagnosis. Even if there were societal unanimity that absence of neocortical function was equivalent to death, the clinical imprecision of this entity would mean prolonged periods of uncertainty about whether a person was alive or dead. Final declaration of neocortical death could then lead to the removal of organs from and/or the burial of warm spontaneously breathing bodies. Not my body, thank you.

If changes in the UAGA or the UDDA are not going to work, the only other way to salvage these organs is to change the third step in the syllogism which says "Live-born babies with anencephaly are not dead." This feat of semantic gymnastics could be accomplished in one of four ways.

First, we could just say "anencephalic babies are dead." The absurdity of saying that a body with spontaneous respiration, spontaneous circulation, and intact primitive reflexes is dead should be obvious. Further, such a declaration of death would deal a major psychological blow to the parents of an anencephalic baby who do not wish to have its organs harvested, but wish to cuddle and nurture him/her until the inevitable natural cessation of breathing. The California legislature refused to pass such a bill in 1986.

Second, we could say that newborns with anencephaly are "brain absent." After all, the word "anencephaly" means just that. The baby with anencephaly has a tragic anomaly which is the result of an error of embryology, but the word anencephaly is an error of taxonomy. These babies are not absent a brain. They have a brain stem with structure and function.

Third, we could say that babies with anencephaly are non-persons as suggested by several philosophers. Killing non-persons for the benefit of persons would then be comparable to using animals for the benefit of humans. If the nebulous concept of personhood were used, we would no longer be obligated to protect or nurture other infants with severe neurological handicaps, children or adults in a persistent vegetative state, or persons with end-stage degenerative brain diseases. But who would be the judge of each person's personhood? At what functional level or I.Q. level would a person slip over the line into non-personhood? Persons are of too much value to be placed in this jeopardy.

The final way to justify the use of organs from individuals with anencephaly is to agree that they are unique and we thus

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thereby make organ donation possible immediately after birth.

Patient autonomy is well accepted today, and in the case of an anencephalic newborn, family autonomy must be strengthened. Because anencephalic newborns are such marginal personal beings, broad parental latitude must reign. Strong reasons exist for allowing parents to decide:

—Parents already make vital decisions in regard to their offspring in deciding for or against abortion—within legally delineated limits. If the possibility of making such a decision in regard to healthy fetuses is permissible, it should be permissible for parents of higher brain-absent newborns to make decisions on organ procurement and donation.

—The basis for deciding the use or nonuse of an anencephalic newborn's organs is rooted in "deep" philosophy, yea, religion. This transplant dilemma has been created by modern medical science, and in this unchartered territory a certain morality will hold sway, even if by default. In areas of such fundamental personal dispute, it is proper in this land of civil and religious liberty to allow parents to make decisions within reasonable limits.

—There are hundreds of other infants who are ill or dying and who potentially could be benefited. Consider only the need for neonatal hearts. Each year in the U.S. an estimated 600 infants are born afflicted with hypoplastic left-heart syndrome, a universally fatal condition until late successes in infant heart surgery and particularly in neonatal heart transplantation.

> ***"If infants like Baby Theresa were used as organ sources, society would have to redefine death."***

—Finally, a decision to donate the organs of one's anencephalic newborn so others might live is a most personal decision arrived at through deeply conflictive emotions. There is mounting evidence that parents want great good for another couple and baby to come from their own personal trauma. Nothing can take away the personal despair of the parents of an anencephalic newborn, but neonatal transplantation now makes possible a partial win-win situation out of what has always been a total lose-lose tragedy.

Because of society's moral division over the life of anencephalic infants, parents of these newborns must not be coerced by the personal beliefs of others. Whether an anencephalic newborn is precious until its last lung of air is breathed, or whether its preciousness lies in donation of organs that another babe might live, should be the parents' choice.

(An expanded version of this piece is in the current issue of ***Biolaw*** and an excerpt recently ran in the ***San Bernardino Sun.***) ■

Orr – Continued from page 7

> ***"The rules about declaration of death and harvesting of organs are rules of major societal importance."***

have limited obligations to them. This concept has been suggested by many and has been used in more than one proposed change in the UAGA and the UDDA. This is the most tenable and most tempting avenue to achieve the desired utilitarian goal. This proposal assumes there is no possibility of misdiagnosis or of expansion into other exceptions. Neither of these assumptions is correct. Anencephaly is an imprecisely defined range of conditions toward one end of a spectrum of congenital malformations related to failure of closure of the neural tube. Variability in anatomy, function and survival as well as confusion with severe microcephaly and other conditions attest to the imprecision. The Loma Linda experience of having many infants referred by outside physicians for inclusion in its anencephaly protocal who had anomalies recognized to be less severe, but who were felt to be logical extensions by the referring physicians, confirm that the slippery slope is real and operative.

The proposed changes to the UDDA are a legal slippery slope. Calling anencephalic babies non-persons is a philosophical slippery slope. Calling them unique is a medical slippery slope. The rules about declaration of death and harvesting of organs are rules of major societal importance. They should not be loose enough to allow any steps onto a slippery slope. Such a slippery slope endangers the humanity and personhood of all of us. ■

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