

NETWORK NEWS

The newsletter of the Florida Bioethics Network

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ORGAN TRANSPLANTATION: ARE ANENCEPHALIC INFANTS SUITABLE DONORS?

The feature article is brought to you from Glenn R. Singer, M.D., F.A.C.P., F.C.C.P., Associate Director, Broward General Medical Center Department of Pulmonary Medicine. The purpose of this article is to present opposing perspectives on the use of anencephalic infants as donors for organ transplantation. A proponent of infant donors is Arthur S. Berger, J. D., member, Broward General Medical Center Ethics Committee and author of many books on bioethics. Offering opposing views are: John Sause, Ph.D., Professor, Philosophy and Theology, Barry University, Miami, Florida; Rabbi Albert Schwartz, Director of Chaplaincy, Jewish Federation of Northern Broward; Reverend Patrick Slevin, St Pius X Church, Ft. Lauderdale; and Reverend Vincent Kelly, St. John the Evangelist Church, Ft. Lauderdale.

An Ounce Of Facts...submitted by **Arthur S. Berger, J.D.**

In March 1992, an infant named Theresa was born at Broward General Medical Center in Fort Lauderdale without a skull or brain and with only a brain stem. Because of her condition, she was doomed to die soon after birth. Her parents wished to donate their infant as an organ source to save the lives of other infants. She was delivered by Caesarian section, intubated and placed on ventilatory support to maximize the chances of using her organs. But in spite of the parents pleas to be able to

donate their child as an organ source, their wishes were rejected by the physicians, the hospital and, later, by the Florida Supreme Court.

Baby Theresa could not be used as an organ source because of the "brain dead" rule which makes someone ineligible as an organ donor if the person still has brain function; in this case, the infant had a brain stem function. The decision by the Florida Supreme Court shows clearly that the courts will not provide any legal method to use anencephalic infants as organ sources. Only the legislature can. Since courts interpret the existing law as prohibiting the use of these infants, the law must be amended to remove the prohibition.

There are at least three alternative legislative amendments which can be proposed. Two are amendments to the Brain Death Statute (F.S. Sec. 382.009) to allow for harvesting organs from anencephalics either by redefining brain death or to exempt anencephalics from the statute. One is an amendment to the Anatomical Gift Act (F.S. Sec. 732.910) and would be to provide that anencephalic infants may be used as a special class of organ source if their parents give free and informed consent to donate their children as organ sources and if these infants are determined and certified as anencephalic by physicians who are not members of any transplant team.

An Ounce Of Facts (continued)

There are good reasons for amending the law. According to statistics put out by the United Network for Organ Sharing, there are 1,300 pediatric patients in need of major organs and the problem is that the supply of small organs they need is not adequate to meet the need. On the other hand, there are 1,000-2,000 anencephalic infants like Baby Theresa born each year with a life span measured in hours, days or a few weeks. Baby Theresa died nine days after her birth. It is impossible at present to prolong their lives or remedy their defect. They are doomed. Their condition prevents them from being sentient, or having the capacity to communicate or be conscious of anyone or anything around them or of feeling pain if organs were to be removed from them. Even though a proportion of these may not provide usable organs, some will and may save the lives of infants who will surely die without them.

There are three other compelling reasons for amending the law. First, there are the parents of the anencephalic infant. If they want, as did Baby Theresa's parents, to donate their infants as organ sources to save other infants, it is for them a way of turning their tragedy to some good and of mitigating their suffering. Second, the medical community is ethically bound to respect autonomy and informed consent and that parents are the best qualified to make medical decisions for their children. Yet the wishes of parents to donate anencephalic children are being thwarted because of the existing law. Amending the law will protect the parents and allow the medical community to honor their wishes. Finally, there are the parents of the infants needing organs. Their hopes will be fulfilled and suffering will be mitigated, too, if the anencephalic's organs can be donated.

In light of these reasons, it is hard to understand why there should be objections to amending the law so as to use anencephalics as donors. Nevertheless, it is argued that: 1) anencephalics have the right to life. All religions teach that life is sacred. But this teaching is as well the basis of our society and laws. The Fifth Amendment of the U.S. Constitution, for example, says that no person shall be deprived of life; 2) anencephalics merit respect as human persons and to the integrity of their bodies and to dignity by virtue of their membership in the human race and human existence; 3) anencephalics as human persons are to be treated as ends and it is wrong to treat them with aggressive medical treatment to preserve their organs and deal with them as means for the purpose of transplanting organs for the benefit of others; 4) if we ease the present law to make anencephalics exceptions as organ sources, this will open the door to abuse. We will not stop with them but will soon extend the exceptions to other imperfect segments of the population and eventually include microencephalic and hydroencephalic infants as well.

My replies to these objections are: 1) Religion and the Constitution may grant the right to life, but it is frequently an empty right since life always can be and is taken in our society. Killing someone in self-defense is allowed. Capital punishment is sanctioned. Killing in war and in law enforcement is accepted in the national or public interest. It is plain hypocrisy to argue that there is any right to life. In the case of the anencephalics, the question is whether they have rights to be protected by the law. The objection assumes that we all have an interest in life. The assumption is correct except in the case of anencephalics. Under the Baby Doe Regulations of 1985, life-sustaining treatment, such as nutrition and

An Ounce Of Facts (continued)

hydration, can be withheld or withdrawn from anencephalics. They are considered as having no interest in or right to life and are permitted to die, because they cannot recover and are not sensate and have none of the experiences or capacities that make life worthwhile. If passively killing the anencephalic by stopping or not starting life-sustaining treatment is justified on this basis, why not be allowed to actively cause the death of the anencephalic by organ retrieval. In either case, the anencephalic has no further interest in living and no longer has a right to life the law should protect. Active killing by organ removal would not infringe this right.

The second point made by objectors raises the basic issue of what constitutes humaneness and personhood. They assume that belonging to the human race and just being born is enough to earn the respect of others for life and bodily integrity. What merits this respect is not just the act of being born into the human species, but having those qualities of humanness and personhood that merit this respect; that is, sentience, consciousness, awareness, responsiveness, the ability to communicate. It is questionable whether an anencephalic who never had these qualities and is without any form of mental life and who only has a human body which functions biologically is entitled to this respect. We should treat as ends those who have our respect and are to be treated with dignity, but anencephalics are not in this class. We should treat as ends those who have an interest in not being physically harmed, however, anencephalics do not have this interest because they are incapable of feeling pain. Harvesting their organs will not cause them harm. So it is not wrong to use them as a means for the benefit of others.

Finally, I reject the minority's "slippery slope" or "domino" or "wedge" argument to the effect that making an exception for the anencephalic as organ sources will not stop with them but will be extended to the unwanted and others, such as microencephalics and hydroencephalics. This argument is at bottom a concern that the category of anencephalics will be so loosely and vaguely defined that it will be misinterpreted and misapplied to anyone who is undesirable. It is a question of definition. But the second proposed amendment to the brain death statute, and the amendment to the anatomical gift statute, both are clearly and specifically limited to "brain absent" anencephalic individuals, a diagnosis that can be made with medical certainty and is one hundred percent accurate. It is impossible for the exception created only for them to be misunderstood, misinterpreted and extended to individuals with less devastating injuries, such as microencephalic or hydroencephalic infants or to other unwanted segments of society, including the old, the mentally defective, or those in a persistent vegetative state or in a coma.

Whatever we think of these arguments, pro or con, they all must be weighed in the light of hard facts. These are: 1) that over 1,000 pediatric patients will die if they do not receive needed organs; 2) there are enough anencephalic infants born every year who can prevent their deaths if the laws are amended to permit them to be used as organ sources, and their parents consent to donation; 3) the suffering of the parents of both the anencephalic donor and the infant recipient of organs will be mitigated; and 4) amending the law will allow the parent's autonomy, informed consent and decisions to be respected as they should be by the medical community.

An Ounce Of Facts (continued)

I believe that an ounce of facts like these outweighs a ton of theoretical, speculative and abstract objections.

The Argument Against Exempting Anencephalic Infants from the Uniform Death Act

No one can argue with the lofty ideals espoused by our distinguished colleagues concerning the potential benefits to a recipient child in need of viable organs, but the means suggested by our colleagues in attaining this goal is indeed questionable. In short, despite the apparent benefits presented by our colleagues in changing the statute concerning the declaration of death solely for anencephalic infants, there is another side of the equation which needs to be seriously addressed, that is the moral costs. It is these costs which we believe exceed the benefits sought by our colleagues.

Deeply embedded in both our religious tradition and system of jurisprudence is the moral principle that "human beings" possess certain "inalienable rights," and these rights exist by virtue of human existence and thereby are unconditional. Precisely because they are unconditional they are likewise, inalienable, that is, cannot be given away or alienated by the consent of others via an informal consensus or formal structure, such as government. In short, government or consensus cannot authorize an alienation of a right which, in essence, they have not bestowed, rather government exists in order to secure that these rights are not violated precisely by an arbitrary consensus. From whom or where do these rights generate? For those of religious faith, particularly the Jewish and Christian tradition, which has greatly informed the ethos of our founding fathers, it is our Creator. From this perspective, human life, whether it be ours or others, is primarily a trust and a gift. As

a trust and gift, we do not have absolute rights in its exercise. We are commissioned by God to relieve the suffering of ourselves and others to the best of our ability, but in no circumstances are we permitted to "solve" the problem of suffering by extinguishing the sufferer solely for purposes of expediency or social utility. For those who do not ascribe to this belief in the Divine, there is still another tradition from which the claims of "inalienable rights" generate, and that is the accumulated history of man's self-defining categorizations. This history essentially posits the belief that we are beings who possess moral intuitions refined through reason which become articulated in formal instruments of declarations, such as Charters, Preambles, Constitutions, Bill of Rights, etc. One of the most fundamental postulates embodied in these august instruments is the assertion that human beings are inviolable. Every human being is entitled to respect by others for his life and the integrity of his person; nor shall anyone arbitrarily deprive that human being of this right. To paraphrase the American Constitution, this can be succinctly stated, "No person ... shall be deprived of life ... without due process of law."

It is this inherent dignity of the human person universally acclaimed in international covenants and substantiated in the American Constitution that we believe becomes diminished should the legislature exempt anencephalic infants from the uniform definition of death. The U.S. Supreme Court in *Cruzan* has stated that persons enjoy a "due process" liberty interest in refusing life-sustaining medical treatment. Understandably, this liberty interest is not absolute, that is, the liberty interest must be balanced against relevant state interests. However, rarely have the courts interfered with this interest to refuse life-sustaining medical treatment, unless the person is the

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sole support of dependent children or possesses a highly communicable disease which, if left untreated, would jeopardize the common good. This is not applicable where the person refusing treatment is the anencephalic infant. Some may argue that an anencephalic infant is not a person and, therefore, warrants no protection under the law. But such is not a defensible case legally. Even Justice Blackmun, writer of the majority opinion in *Roe v. Wade*, despite whether the undersigned members concur with his opinion that a mother's rights takes precedence over her pre-viable child's life, drew the bright line by stating emphatically, "the word 'person,' as used in the Fourteenth Amendment does not include the unborn." Hence, those born merit the legal term "person" and anencephalic infants, despite their severe maladies, are born and therefore entitled to the same legal rights accorded to all other newly born citizens. Nor does the Constitution, according to the *Cruzan* decision, diminish in any way this right to refuse life-sustaining treatment based upon the number [or lack] of qualities the person possesses.

If the person lacks decision making capacity, such as the case of the anencephalic infant, it does not in any way disqualify the infant in exercising his/her legal rights to refuse life sustaining treatment. The exercise of this right usually inures to the parent or court appointed guardian whom it is presumed will act in the best interests of the child (the usual substitute judgement guiding principle in this case is not applicable since we do not directly know nor possess a value history from which to derive what would be the choices of treatment or its refusal by the child in this matter). The question now arises as to what is in the best interests of

the child? It is precisely this principle of beneficence, or stated in the common negative injunction parlance, *primum non nocere* (first, do no harm), which has informed medical ethics for millennia. It is our contention that this cherished principle will become speciously circumscribed in its scope should the opinion advocated by the majority of our colleagues gain acceptance. It is their view that the infant's organs should be perfused for however long or minimally it takes to optimally procure a match for a viable transplant. Thus, the prospective recipient child becomes the primary concern and the "donor" anencephalic infant's right to refuse "unwarranted" medical intervention is abrogated. We say unwarranted because presumably the removal of a viable body organ has no immediate benefit to the patient, and we certainly do not know the child's wishes in this regard, thus precluding the substituted judgment principle as the guide. Nor may parents, regardless of how noble their intent, in the words of the Supreme Court "make martyrs of their children (*Prince v. Massachusetts* 323 U.S. 170, 1944). Only by maintaining the current definition of total brain death can we expect the anencephalic child's right from unwarranted medical intrusion to remain inviolable.

We are sure our colleagues in the majority have cited several noted ethicists who have taken a position in favor of their own argument for change. Let us assure you that list of ethicists supporting our stance is no less persuasive or reputable in the discipline of medical ethics. Essentially, the ethicists in our camp base their refusal of changing the law concerning the definition of death regarding anencephalic infants upon two moral principles and one persuasive argument. One principle (known as the Kantian principle of personality) states that

The Argument Against Exempting Anencephalic Infants from the Uniform Death Act (continued)

human persons are of inestimable value and are always to be treated as ends and not a means. To artificially maintain the anencephalic infant [presumably without the child's consent] for the sole purpose of organ transplanting without any immediate benefit to the infant patient is a violation of this principle. The second, which has largely informed the discipline of medical ethics, is the principle of double effect. This principle states "the good intended cannot be obtained by means of an evil effect." Applying this to the issue of anencephalic infants, the good (potential organ transplant benefiting other infants) cannot be obtained by the means of evil (artificially prolonging or the shortening of the child's dying process by the direct removal of a viable organ).

Finally, the persuasive argument utilized by ethicists in our fraternity is often referred as the "slippery slope" polemic. This states that to ease the present determination of death for the sole purpose of harvesting organs from anencephalic infants relegates them to the level of "non-persons." It will only be a matter of time until further relaxation of the standards for personhood occurs and other less perfect members of society are labeled as "non-persons." Our colleagues scoff at this argument, claiming that we are "grasping at straws" using the most remote probability to prevent the putative benefits that can be gleaned by making this one exception concerning anencephalic infants. In short, they denigrate our position to the status of mere whimsical rhetoric. One merely needs to review the Dutch experience concerning patient voluntary euthanasia assisted by physicians to realize the cogency of the slippery slope argument. Initially, strict

guidelines were established: euthanasia cannot be performed unless it be the culmination of repeated requests of the terminable competent patient over a reasonable period of time in the throes of suffering that has no prospect of relief. These guidelines established by the courts and the Dutch Medical Association have been essentially disregarded. Dr. John Keown, Director of the Center for Health Care Law, at the University of Lancaster in England, has stated that recent studies by the Dutch government itself revealed, "Dutch doctors admitted that in 1990 they sought to kill some 20,000 patients and that, in a clear majority of cases, this was done without the patient's consent." ("Dutch Slide Down Euthanasia's Slippery Slope," *Wall Street Journal*, November 5, 1991 A-12). Can we be so self-assured that a comparable experience regarding anencephalic infants will not occur? Can our colleagues in the majority guarantee that the exception line clearly demarcated for anencephalic infants only not become gradually blurred to eventually include microencephalic and hydroencephalic infants?

Finally, we do not wish to convey that we are insensitive to the poignant needs of the parents of the anencephalic child and the heartfelt hopes of the parents of the potential recipient child. Our position is that we protect the rights of the donor and the recipient equally. To this end, we see no ethical violation in the administration of customary medical care to the anencephalic infant until, to a reasonable degree of medical certainty, the impending signs of cardiorespiratory death surface. At which time, infants are given maximal life support and closely monitored for total loss of brain function. "The retrieval and transplantation of organs of anencephalic infants are ethically permissible only after such determination of death is made, and in

The Argument Against Exempting Anencephalic Infants from the Uniform Death Act (continued)

accordance with the Council's guidelines for transplantation of organs." (" 1992 Code of Medical Ethics - Annotated Current Opinions 2:162," *Council on Ethical and Judicial Affairs of the American Medical Association*). Our own State Supreme Court has expressly concurred with our position for "the evidence shows that T.A.C.P.'s heart was beating and she was breathing at the times in question; accordingly, she was not dead under Florida law, and no donation of her organs would have been legal." (*In Re: T.A.C.P.* 17 FLW S694, 1992). Such a unanimous decision by our Justices does not merit overruling by legislative *fiat* rather the principles that undergird their consensus whether ethical or legal remain cogent, enduring and inviolable.

LETTER FROM THE EDITOR. . . .

submitted by Mary Lou Jones, Co-Director/Perinatal Pediatrics, Florida Hospital Medical Center, Orlando.

The FBN Newsletter is being reorganized to improve the quality of ethics information. In each issue, there will be a feature article representing opposing perspectives in various ethical dilemmas. The purpose of this article will be to showcase different perspectives to facilitate dialogue on these dilemmas. Readers are invited to submit questions and comments regarding ethical dilemmas to me at Florida Hospital Medical Center, 601 E. Rollins Street, Orlando, FL 32803-1287 -- 407/897-1963.

Additionally, there will be legislative updates on activities in process on a state level, and a President's message. Finally, educational resources such as conference announcements and bibliography of publications will be included.

LEGISLATIVE UPDATE. . . . submitted by John Babka, M.D., Senior V.P., Director of Medical Affairs, Morton Plant Hospital, Clearwater.

This is the fourth column describing the features of the newly rewritten Florida Statute §765 RIGHT TO DECLINE LIFE-PROLONGING PROCEDURES. Previous columns have specifically described the procedures for using a surrogate and selection and use of a healthcare proxy; this will describe the features of a living will.

Any competent adult may at any time make a living will or a written declaration directing the providing, withholding, or withdrawal of life prolonging procedures in the event such person suffers from a terminal condition. The living will must be signed by the maker in the presence of two witnesses, one of whom may not be the spouse or a blood relative. The principal must provide notification to his physician that the living will has been made. If he is mentally incapacitated when he is admitted to a healthcare facility, anyone may notify the physician or healthcare facility of the existence of the living will. The physician or healthcare facility, so notified, shall promptly make the living will, or a copy thereof, a part of the medical record. This living will establishes a rebuttable presumption of clear, convincing evidence of the principal's wishes.

In several places, the term "terminal condition" is used. Most experts consider this term to include conditions, such as, a persistent vegetative state or permanent coma, or other similar condition from which there is no hope of recovery. For example, if we do not artificially feed and/or hydrate a person in coma they would soon die, i. e. their condition is terminal without artificial support. Any other definition would be so

LEGISLATIVE UPDATE (continued)

limited as to severely constrain the practical use of these provisions.

The living will is to be used when, and only when, the principal is not competent to make his own decisions. Before acting in accord with the direction of the living will, the surrogate or proxy, as defined previously, must be satisfied that: a) the principal does not have a reasonable probability of recovering competency so that the right could be exercised directly by the principal; b) the principal's physical condition is terminal; and c) any limitations or conditions expressed orally or in a written declaration have been carefully considered and satisfied. If a surrogate or proxy cannot be found, the healthcare facility may proceed as directed by the principal in the living will.

The law contains a suggested form for a living will, but this form is not required. I have included a copy of a living will which my institution has developed. Our community likes it very much. The living will may take almost any form, as long as it expresses the intent of the person executing it. There is no need to have the signatures notarized, nor is there any need to have the living will executed by an attorney.

In determining whether the patient has a terminal condition or may recover capacity, or whether a medical condition or limitation referred to in an advanced directive exists, the patient's attending physician and at least one other physician must separately examine the patient. The findings of these examinations must be documented in the medical record by each physician before life-prolonging procedures may be withheld or withdrawn. [As a practical matter, when the situation is clear and all parties agree, many institutions do not require the second opinion.]

The law specifies that nothing in it shall be construed to condone authorized or approved mercy killing or euthanasia, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying. This withholding or withdrawal of support does not constitute suicide.

PRESIDENT'S MESSAGE. . . Esther Sangster, RN, FBN President.

Nineteen ninety-two marked the sixth anniversary of the Tuskegee syphilis study. This study, of the effects of untreated syphilis on 400 black men in Tuskegee, Alabama, is well known for its lack of ethics and moral judgment.

Sixty years later we use informed consent, IRBs, ethics committees, legislation and the courts to protect patients from unethical or illegal practices. The increase in the formation of institutional ethics committees has helped to crystalize the need for collaborative decision making among health care practitioners, patients and families.

How many ethics committees are currently providing consultation? We would like to hear from you and learn more about what is happening in your institution. Send us a letter telling us about your committee and its function. We will publish your information in the newsletter.

The purpose of FBN is to provide a network across the state. This network only works if we take advantage of it. Write us or call the board members to discuss issues or concerns. Let's work together to influence state and institutional policy for the good of our patients, their families and our practices.

PRESIDENT'S MESSAGE (continued)

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MEETINGS OF INTEREST

FBN Annual Meeting and Conference has been scheduled for October 21-22, 1993 at the Sheraton Plaza Hotel at The Florida Mall in Orlando. FBN President-Elect Jim Wagner is in charge of the program committee. Any suggestions on content or

speakers should be directed to him at 904/395-0123.

Legal and Ethical Issues Facing Florida Medicine will be presented by the University of Florida, College of Medicine on May 20-21, 1993 at the Gainesville Hilton. This program offers an extensive review of legal and ethical issues that specifically confront physicians and nurses. Further information can be obtained from the Continuing Medical Education office at 904/392-3143.

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