

## CEJA Report 5 – I-94 The Use of Anencephalic Neonates as Organ Donors

### INTRODUCTION

Hundreds of children die each year of cardiac, hepatic or renal failure because there are not enough hearts, livers or kidneys available for transplantation from other children. Consequently, various measures have been considered over the years to increase the organ supply for pediatric transplantation. One approach that has received particular attention is the possibility of using organs from anencephalic neonates.<sup>1,2,3</sup> Because anencephalics face a certain and generally imminent death and because they lack any degree of consciousness, many commentators have proposed that organs of anencephalics be used for transplantation, and many parents of such neonates request that their child's organs be given to other children. Permitting such organ donation would allow some good to come from a truly tragic situation, providing psychological relief for those parents who wish to give meaning to the short life of the anencephalic by attempting to save the life of another child. Indeed, two years ago, parents of an anencephalic neonate went before the Florida Supreme Court seeking permission to donate their anencephalic child's organs.<sup>4</sup> However, under current law, which requires persons to be dead before their life-sustaining organs may be removed for transplantation, it is not possible to use the organs of anencephalics. Accordingly, the Florida Court denied the parents' request, and the use of organs from anencephalic neonates remains a matter of debate rather than practice.

In 1988, this Council examined the ethical issues surrounding the use of organs from anencephalic neonates and concluded that it is ethically acceptable to remove organs from anencephalics only after they have died, whether the death occurs by cessation of cardiac function or brain function.<sup>5</sup> In June 1994, after more than a year of deliberation, the Council revised its position and issued a new opinion. The new opinion states that it is ethically acceptable to transplant the organs of anencephalic neonates even before the neonates die, as long as there is parental consent and certain other safeguards are followed.<sup>6</sup> In this report, the Council presents its rationale for changing its position. The Council recognizes that, even with a change in its position, current law would have to be modified to permit parental donation of organs from an anencephalic neonate before the death of the neonate. In the past, the law has often changed to reflect evolutions in ethical thought. Indeed, a report by a committee at Harvard Medical School spurred the modification of the definition of death to mean either the complete cessation of cardiac function or the complete cessation of brain function.<sup>7</sup> The Council presents this report in the hope that it will generate a similar consensus in favor of permitting parental donation of organs from anencephalic neonates before the neonates die.

### SHORTAGE OF ORGANS FOR TRANSPLANTATION IN INFANTS AND YOUNG CHILDREN

For patients of all ages, the demand for organs far outweighs the supply; the shortage of organs is particularly acute when the patient needing the transplant is a young child or infant.<sup>8,9,10</sup> Newborns and other young children usually can benefit from organ transplants only if the organs are taken from children of similar size. However, there is a serious shortage of pediatric organ donors. As a result, each year approximately 500 children need heart transplants, another 500 need liver replacements and approximately 400-500 children in the United States need kidney transplants.<sup>12</sup> With the scarcity of hearts, livers and kidneys available for transplantation, between 30 and 50 percent of children under the age of two years die while waiting for transplants. Overall, 40 to 70 percent of children on the transplant waiting list die while waiting for a suitable organ. These figures are undoubtedly underestimates of the shortage of pediatric organs. With the long waiting lists for the organs, many children in need never make it on the lists because they would not have high enough priority to receive an organ or because they do not

live long enough to have their names entered on the waiting list. Some commentators have therefore proposed that parents be allowed to donate organs from anencephalic neonates for transplantation.

## ANENCEPHALY

Anencephaly is a developmental abnormality of the central nervous system that results in the "congenital absence of a major portion of the brain, skull, and scalp."<sup>14</sup> Because anencephalic neonates lack functioning cerebral hemispheres, they never experience any degree of consciousness.<sup>14,15(p.1575)</sup> They never have thoughts, feelings, sensations, desires or emotions. There is no purposeful action, social interaction, memory, pain or suffering. Anencephalic neonates have fully or partially functioning brainstem tissue. Accordingly, they are able to maintain at least some of the body's autonomic function (i.e., unconscious activity), including the functions of the heart, lungs, kidneys and intestinal tract, as well as certain reflex actions. They may be able to breathe, suck, engage in spontaneous movements of their eyes, arms and legs, respond to noxious stimuli with crying or avoidance maneuvers and exhibit facial expressions typical of healthy infants.<sup>14 (pp.671-672)</sup> While all of this activity gives the appearance that the anencephalic neonate has some degree of consciousness, there is none. Anencephalic neonates are totally unaware of their existence and the environment in which they live.

The lifespan of an anencephalic neonate is generally very short. Many die within a few hours, less than half survive more than a day,<sup>16</sup> and fewer than ten percent survive more than a week.<sup>14 (p.671)</sup> However, because these neonates often do not receive aggressive treatment, their potential lifespan is probably longer than their actual lifespan.<sup>14 (p.671)</sup>

## BENEFITS OF PERMITTING PARENTAL DONATION OF ORGANS FROM ANENCEPHALIC NEONATES

The argument in favor of parental donation of organs from anencephalic neonates is compelling. Many children will be saved from death; many other children will realize a substantial improvement in their quality of life. As Benjamin Freedman has observed, "organ transplantation is not simply an ethical enterprise but one that is, in its current stage of development, a moral imperative" for society.<sup>17</sup>

Organ transplantation from anencephalic neonates can bring profound benefit not only to the recipients of the organs but also to the anencephalic's parents. When confronted with the tragedy of bearing a child who can never experience consciousness and who will die in a matter of days, parents may find much of their psychological distress alleviated by the good that results from donating their child's organs and thereby providing life-saving benefits to other children. Indeed, many parents of anencephalic neonates very much want to donate the organs of their anencephalic offspring to children whose only hope for life is an organ transplant.<sup>3(p.923),4 (p.589),18</sup>

## OBJECTIONS TO PARENTAL DONATION OF ORGANS FROM ANENCEPHALIC NEONATES

Several objections are commonly raised against proposals for parental donation of organs from anencephalic neonates: (1) donation violates the prohibition against removal of life-necessary organs from living persons, (2) false diagnosis of anencephaly may result in the death of neonates who could achieve consciousness, (3) permitting donation from anencephalics may open the door to organ removal from patients who are in a persistent vegetative state or in other severely disabling conditions, (4) anencephalic neonates would rarely be a source of organs for transplantation and (5) allowing donation of organs from anencephalic neonates will undermine public confidence in the organ transplantation system. As discussed below, however, these concerns do not justify a prohibition on parental donation of organs from anencephalic infants.

### *Prohibition Against Removal from Living Persons*

Both law and ethics require that persons be dead before their life-necessary, non-renewable organs are taken (the "dead donor" rule).<sup>19</sup> In his critical principle ensures that one person's life will not be sacrificed for the benefit of another person, even to preserve the life of that other person. While this principle must be vigorously maintained, it must not be applied without regard to whether its application serves its purposes. Upon consideration of the purposes of the general prohibition against removal of life-necessary organs before death, it is clear that those purposes would not be compromised by permitting parental donation of organs from anencephalic neonates.

#### Protecting the interests of persons from whom organs are taken

Ordinarily, the dead donor rule protects the fundamental interest in life of persons from whom organs are taken. However, it does not make sense to speak of an interest of anencephalic neonates in staying alive. Because they have never experienced consciousness and will never experience consciousness, anencephalic neonates cannot have interests of any kind.<sup>20</sup> They cannot experience any pleasure or pain; they have no thoughts, memories or sensations; and they have no ability to communicate. If their lives are shortened, they lose days of life, but they have no awareness of that loss. If there is a loss, it is a loss for others, whether for their parents or society generally. Similarly, the value in the life of an anencephalic neonate is a value only for others. The neonate feels no better or worse by living longer or by not living at all. Accordingly, prohibiting parental donation of organs from anencephalic neonates cannot be justified in terms of protecting the interests of the neonates themselves.

#### Providing reassurance to other individuals

By protecting the interests of persons from whom organs are taken, the dead donor rule provides reassurance to other individuals that, if they choose to become organ donors, their lives will not be shortened by the removal of their organs for the benefit of someone in need of an organ transplant. While this is a critical purpose of the dead donor rule, parental donation of organs from anencephalic neonates will not undermine the rule's reassuring role. People who are contemplating organ donation never can become anencephalic. Accordingly, even if an exception to the dead donor rule is created for anencephalic neonates, people contemplating organ donation will know that they will still receive the protection of the dead donor rule.

#### Preserving the moral worth of society

The dead donor rule, like other prohibitions against killing, reflects the high value that society places on life and emphasizes that all life must be respected and treated with dignity, whatever the quality of the life.<sup>21</sup> While respect for life is a value of utmost importance, it is not clear what implications that value has for the treatment of anencephalic neonates. Because the anencephalic neonate is incapable of having an interest in staying alive, respect for the essential worth of the anencephalic does not necessarily entail the preservation of its life. Indeed, it is well accepted that parents of anencephalic neonates always have the option of discontinuing life-sustaining treatment for anencephalic neonates, and a Fairfax, Virginia hospital unsuccessfully went to court arguing that life-sustaining treatment for an anencephalic neonate need not be continued even if the parents wish to continue the treatment.<sup>22</sup> When life-sustaining treatment is discontinued, society shows its respect for the anencephalic neonate by treating the neonate as it would any other terminally ill patient whose life-sustaining treatment is being discontinued. The neonate's corpse may not be desecrated, and the deceased neonate is given a proper burial. Similarly, because the anencephalic infant is incapable of having an interest in staying alive, respect for the essential worth of the anencephalic neonate does not necessarily entail a prohibition on parental donation of the

anencephalic neonate's organs before its' death. Instead, society should show its respect for the anencephalic neonate by treating it as it does persons whose organs are removed for transplantation after their death.

### *Accuracy of Diagnosis*

There has been concern that allowing parental donation of organs from anencephalic neonates could lead to parental donation of organs from infants with similar severe conditions, but who are not anencephalic.<sup>23</sup> Indeed, when researchers at Loma Linda University Medical Center conducted a protocol involving anencephalic neonates, some physicians referred infants to the protocol who were not in fact anencephalic (*AMNews*, July 25, 1994:14). Misdiagnoses of infants as anencephalic have been documented in the medical literature and detected by surveillance programs.<sup>14(p.670)</sup>

Nevertheless, while the Possibility of misdiagnoses cannot be entirely eliminated, it can readily be reduced to an insignificant level with the adoption of appropriate safeguards. The diagnosis of anencephaly is highly reliable. As the Medical Task Force on Anencephaly observed, "[the appearance of the infant with anencephaly is unique, and the diagnosis can be made with virtual certainty when [the four defining] criteria [of anencephaly] are met."<sup>14(p.670)</sup> A prominent critic of parental donation, of organs from anencephalic neonates has written that "[in the great majority of cases, the diagnosis of anencephaly is very obvious, and there is little, if any, chance of mistaking it for another condition."<sup>24</sup> With such a high degree of certainty, it is unlikely that anencephaly would be any more difficult (and perhaps even easier) to diagnose than brain death, which is currently accepted as a basis for organ donation from other patients. Problems with diagnosis of anencephaly occur primarily because the diagnosis is being made by a physician with insufficient expertise; as a corollary, there is little risk of misdiagnosis when the diagnosis is made by a physician with sufficient expertise. To ensure that the diagnosis of anencephaly is as accurate as possible, the diagnosis should be confirmed by two physicians with special expertise in diagnosing anencephaly who are not part of the organ transplant team. In some cases, even with the involvement of experts, it will not be clear whether the neonate is anencephalic. (p.670) In such cases, as others have argued, (p.389) parental donation of the organs should be prohibited until the neonate has died.

### *Slippery Slope Concerns*

Some commentators oppose parental donation of organs from anencephalic neonates based on their belief that it would open the door to abuses of other persons: creating an exception to the dead donor rule to use organs from anencephalics may result in further exceptions to enable organ removal from other seriously handicapped persons.<sup>26(p.8)</sup> For example, many fear that individuals who are in a persistent vegetative state,<sup>23 (p.1776)</sup> infants with seriously disabling conditions and elderly adults with severe dementia<sup>26 (p.8)</sup> would also be considered acceptable sources of organs.

The problem with this argument, as with other slippery slope arguments, is that any change in policy can be challenged on slippery slope grounds. When patients requested permission to reject life-sustaining treatment, opponents argued that granting such permission would open the way to euthanasia. Permitting the use of contraceptives, particularly those that work after fertilization, opens the way to abortion. It is not enough, therefore, simply to invoke a slippery slope argument. Rather, it must be shown that the slippery slope risk is a serious one in the particular issue under consideration.

There is an important reason why the slippery slope risk is not a serious one if society decides to permit parental donation of organs from anencephalic neonates. Anencephalic neonates are unique among persons because they have no history of consciousness and no possibility of ever being conscious. Infants

with other severely disabling conditions have at least some degree of consciousness as do elderly persons with severe dementia. Accordingly, unlike anencephalic neonates, severely disabled infants and adults have interests, including interests in staying alive. While patients who are in a persistent vegetative state no longer are conscious, they once were conscious and have therefore previously established an identity and a set of interests. In short, because anencephalic neonates and other disabled persons differ on the very factor that justifies parental donation of organs from anencephalics, there is little force to the analogy between organ removal from anencephalics and organ removal from other persons with severely disabling conditions.

### *Number of Children Who Would Benefit*

Critics of parental donation of organs from anencephalic neonates have argued that too few children would benefit from the organs of anencephalics. These critics observe that, while estimates of the number of anencephalic births generally are within the range of 1,000 to 2,000 births per year,<sup>11 (p.1116), 14 (p.671), 23 (p.1774)</sup> most anencephalic neonates are stillborn, and organs from some liveborn anencephalics are not suitable for transplantation.<sup>23 (p.1774)</sup> As a result, the number of children who could benefit from the organs of anencephalics may be considerably smaller than 1,000; indeed, according to one estimate, only about 20 infants a year would gain a long term survival from a heart or liver transplant, and only another 25 infants would receive a long-term benefit from kidney transplantation.<sup>23 (p.1775)</sup>

This concern about the number of children who would benefit should not be a barrier to parental donation of organs from anencephalic neonates. First, the estimates are probably much too low. The estimate of only 20 long-term survivals from heart or liver transplants depends upon a series of assumptions, most of which are unreliable. According to one assumption, only 40% of liveborn anencephalics would have birth weights high enough for them to have usable organs. In addition, the estimate assumes that another 15-25% of hearts and livers will not be usable because of malformations.<sup>23 (p.1774)</sup> Yet, in a study of twelve liveborn anencephalics, researchers found that, upon admission of the neonates to the study protocol, the hearts and livers of almost all the neonates were suitable for transplantation.<sup>13 (pp.346-348)</sup> The estimate also assumes that no more than 25% of usable organs would actually be used.<sup>23 (p.1775)</sup> However, because of advances in organ transplantation technology in the six years since this assumption was made, it is likely that many more organs would be usable. Each anencephalic may be able to provide four life-saving organs (heart, liver and kidneys). More importantly, even assuming that there would be only 20 long-term survivals gained each year and that only long-term survivals matter, it is not clear why that should be an objection to parental donation of organs from anencephalic neonates. Among the different goals that health care can achieve, saving lives is of fundamental importance; indeed, it is never insignificant to save 20 lives.

To be sure, there are limits to the price that society can or should pay to save lives, but none of the other arguments against parental donation of organs from anencephalics suggest that such limits would be reached if parental donation were permitted.

### *Public Trust in the Organ Procurement System*

Some commentators suggest that creating an exception to the dead donor rule may undermine society's confidence in the organ procurement system and cause a chilling effect on overall organ donations.<sup>11(p.1119),23(p.1776)</sup> However, the modification of the definition of death to include the complete cessation of brain function was a far more fundamental change in social policy than the change proposed here, and the move to brain-based conceptions of death occurred explicitly to facilitate organ procurement.<sup>7</sup> Inasmuch as that change has not undermined public trust in the organ procurement system, there is little reason to think that parental donation of organs from anencephalic neonates would undermine public trust. In addition, while it is true that existing organ procurement practices should not be changed without due

deliberation, change should be possible in response to important, unmet social needs and evolving understanding of the ethical and scientific issues surrounding anencephaly. Accordingly, rather than prohibiting parental donation of organs from anencephalic neonates, certain safeguards should be employed to preserve public trust in the organ procurement system. First, parental donation of organs from anencephalic neonates should occur only if the discussion of donation is initiated by the parents of the neonates, not if it is initiated by members of the health care team. Second, parental donation should not occur without the fully informed consent of the parents of the anencephalic neonate. Third, a pilot program for parental donation of organs from anencephalic neonates should be undertaken to assess its impact before the practice becomes widespread.

## CONCLUSION

For the reasons described above, the Council has developed the following opinion, which has been revised minimally since its original issuance in June 1994 to clarify the Council's intent (substantive additions are italicized):

*2.162 Anencephalic Neonates as Organ Donors.* Anencephaly is a congenital absence of a major portion of the brain, skull, and scalp. Neonates with this condition are born without a forebrain and without a cerebrum. While anencephalics are born with a rudimentary functional brain stem, their lack of a functioning cerebrum permanently forecloses the possibility of consciousness.

It is ethically permissible to consider the anencephalic as a potential organ donor, although still alive under the current definition of death, only if: (1) the diagnosis of anencephaly is certain and is confirmed by two physicians *with special expertise* who are not part of the organ transplant team; (2) the parents of the neonate *initiate any discussions about organ retrieval* and indicate their desire for retrieval in writing; and (3) there is compliance with the Council's Guidelines for the Transplantation of Organs (see Opinion 2.16, Organ Transplantation Guidelines).

In the alternative, a family wishing to donate the organs of their anencephalic neonate may choose to provide the neonate with ventilator assistance and other medical therapies that might sustain organ perfusion and viability until such time as a determination of death can be made in accordance with current medical standards and relevant law. In this situation, the family should be informed of the possibility that the organs might deteriorate in the process, rendering them unsuitable for trans-plantation.

It is normally required that a person be legally dead before removal of their life-necessary organs ("Dead Donor Rule"). The use of the anencephalic neonate as a live donor is a limited exception to the general standard because of the fact that the infant has never experienced, and will never experience, consciousness.

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