



# Policy Statement—Pediatric Organ Donation and Transplantation

## abstract

Pediatric organ donation and organ transplantation can have a significant life-extending benefit to the young recipients of these organs and a high emotional impact on donor and recipient families. Pediatricians, pediatric medical specialists, and pediatric transplant surgeons need to be better acquainted with evolving national strategies that involve organ procurement and organ transplantation to help acquaint families with the benefits and risks of organ donation and transplantation. Efforts of pediatric professionals are needed to shape public policies to provide a system in which procurement, distribution, and cost are fair and equitable to children and adults. Major issues of concern are availability of and access to donor organs; oversight and control of the process; pediatric medical and surgical consultation and continued care throughout the organ-donation and transplantation process; ethical, social, financial, and follow-up issues; insurance-coverage issues; and public awareness of the need for organ donors of all ages.

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## BACKGROUND

In 1998, the Centers for Medicare and Medicaid Services changed the federal conditions of participation to require that hospitals participating in Medicare and Medicaid programs refer potential organ donors to their local organ-procurement organization (OPO) in a timely manner.<sup>1</sup> The Centers for Medicare and Medicaid Services mandates that all families of potential organ donors be made aware of their option to donate. Legislation further requires all hospitals to have trained “designated requestors” available to discuss organ donation with families of potential donors. Even with these mandates, organ availability remains inadequate. The number of individuals who are on the national transplant waiting list remains far in excess of the number of organs recovered and transplanted.<sup>2</sup> Children from birth to 17 years of age account for approximately 2% to 3% of the national waiting list. More than 70% of the children on the list are waiting for a liver or a kidney, and the small bowel is the organ with the greatest increase in need.<sup>3,4</sup> Ongoing debates attempt to identify the best ways to manage the existing supply of organs and how to improve organ procurement in general.<sup>5</sup>

The Organ Procurement and Transplantation Network (OPTN) is the nation’s organ procurement, donation, and transplantation system. The United Network for Organ Sharing (UNOS) is the nonprofit organization that operates under the OPTN under a contract from the federal

COMMITTEE ON HOSPITAL CARE, SECTION ON SURGERY, AND SECTION ON CRITICAL CARE

### KEY WORDS

organ donor, organ donation, organ transplantation, organ procurement, pediatrics, children, ethics

### ABBREVIATIONS

OPO—organ-procurement organization

OPTN—Organ Procurement and Transplantation Network

DCD—donation after cardiac death

UNOS—United Network for Organ Sharing

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government. All organ procurement organizations (OPOs) and transplant programs are OPTN/UNOS members and follow OPTN policies. The OPTN is overseen by the US Department of Health and Human Services, Health Resources and Services Administration. The Children's Health Act,<sup>6</sup> which was passed in October 2000, called on the OPTN to develop specific criteria, policies, and procedures to address the unique needs of children and adults. To overcome the ethical dilemma of organ distribution based on time on the waiting list versus benefit to the patient, the OPTN developed new criteria for organ transplantation for children and adolescents. Included is a new lung-allocation score to maximize benefits and fairness for allocation of donor lungs to potential transplant recipients. This lung-allocation score for patients aged 12 years and older is based on multiple factors, not just the length of time on the transplant waiting list, and allows children to receive priority for pediatric donor lungs before they can be offered to adults. Liver allocation to children on the transplant waiting list is based on the pediatric end-stage liver disease (PELD) and model for end-stage liver disease (MELD) scores and not only on the length of time on the transplant waiting list.<sup>7,8</sup> Kidney-allocation policies are revised so that kidneys from donors younger than 35 years are offered preferentially to pediatric candidates. Children younger than 11 years on the kidney transplant waiting list are given additional priority because of the greater impact of kidney failure on development.<sup>3</sup> Pediatric heart transplantation candidates receive preference over adult candidates in the allocation of adolescent donor hearts depending on the urgency of each case.<sup>3</sup>

## ORGAN DONATION

This discussion of organ donation and transplantation acknowledges that

this is a most difficult time for 2 families: one with a loved one who has suffered an untimely death and another with a child with a terminal condition. Organ donation is a process that starts when the family begins receiving information about their critically ill child.

The American Academy of Pediatrics supports the role of OPOs by recommending that all potential donor families be approached in a systematic method by individuals trained in the psychological, social, and medical aspects of organ donation. OPOs exist throughout the country. They evaluate potential donors, discuss donation with family members, arrange for surgical removal of donated organs, and arrange for distribution of the organs according to national organ-sharing policies. The rate of families that consent to donation can be increased significantly by using hospital or OPO staff who are specifically trained in organ procurement and by separating or "decoupling" the death notification and organ-donation consent processes.<sup>4,9–11</sup> Timely referral and the use of staff trained in organ procurement are federal requirements for participation in the Medicare program. Timely referral is crucial to ensure that a rushed approach regarding donation is avoided with the family. This may start in the emergency department with the admission of a critically injured child, and staff may start the process at that time.<sup>12</sup> Timely referral provides active communication with the health care team and the OPO, which enhances the chances that the family will agree to organ donation. Deliberation with the OPO should occur before or when initial brain-death testing is occurring or "withdrawal-of-care" or "do-not-resuscitate" options are being discussed. Collaboration with physicians, the health care team, and the OPO is critical to ensure that every family is provided the opportunity

to discuss organ donation during end-of-life discussions.<sup>15</sup> Accurate determination of death is essential before efforts to actively recover organs can proceed. One must ensure that death has occurred; if there is any question, additional testing or extending the observation period between neurologic examinations is warranted. Just as important is the timely declaration of neurologic death. Therefore, timely and definitive treatment of the donor is critical.<sup>10</sup> The timely declaration of neurologic death has important benefits. First, it allows the grieving process to begin for the family, which makes a point of closure more likely to be achieved by the family. Second, it improves the success associated with the acquisition of organs. Aggressive medical management of the potential donor to keep organs perfused can increase organ yield. Progression of organ failure secondary to hemodynamic instability after neurologic death results in the loss of up to 25% of potential donors. Third, it avoids continued life support for a person who has died and is no longer a potential donor. Care of the pediatric donor is a natural extension of care for a critically ill and injured child and the family. This continuum of care of the potential pediatric donor and the family is crucial in helping families understand what has transpired with their child. Likewise, support and advice of the child's primary caregiver provides further continuity of care.

Pediatric donors become eligible for organ procurement after the determination of neurologic death has been made. Although most pediatric donors will meet standard criteria for declaration of brain death, donation after cardiac death (DCD)—or non-heart-beating organ donation—has the potential to increase organ donation.<sup>14</sup> Contrary to the belief that DCD is a new way to recover organs, DCD is, in fact,

the foundation of modern transplantation. Organs were routinely recovered from deceased donors by this method before development of brain-death guidelines. For patients with severe brain injury for whom neurologic death is unlikely to occur, DCD enters the end-of-life continuum of care. Discussions regarding DCD can occur only after the family and the medical team have made the decision to withdraw support or terminate care. Comfort measures are provided for the patient as would normally be instituted anytime withdrawal of support occurs. Once life support is withdrawn and the donor develops circulatory arrest, apnea, and unresponsiveness, the patient is observed for a period of 2 to 5 minutes before certification of death. Organs can be recovered for transplantation if death occurs within a short period of time, usually 1 hour, after withdrawal of support. DCD is slowly gaining acceptance in the pediatric community, as evidenced by an increase in organs from pediatric non-heart-beating organ donors over the past few years.<sup>3,4</sup> DCD enables the ability to recover 2 of the most needed organs for children—kidney and liver. Concerns regarding prolonged ischemia time and graft dysfunction have been raised; however, several reports have indicated that renal and liver grafts from DCD donors have graft function and transplant recipient survival rates comparable to those with organs recovered from brain-dead donors.<sup>15–19</sup> In addition, lungs from DCD donors are now being recovered with good success.<sup>9</sup> The Institute of Medicine and the American College of Critical Care Medicine both endorse DCD as a means to recover organs for transplantation.<sup>20,21</sup>

## TRANSPLANTATION

The process of organ transplantation begins when the child is referred to a transplant center. When it is deter-

mined that the child is a suitable candidate, he or she is added to that transplant center's waiting list through the United Network for Organ Sharing (UNOS) computer, and access information for organ-matching is listed. The UNOS is contracted with the Health Services and Resources Administration to maintain a centralized computer network linking OPOs with transplant centers. When a potential organ donor is identified, a transplant coordinator accesses the UNOS computer. The computer generates a ranked list of potential recipients for each organ that may be procured according to organ-allocation policies, which differ for each organ. These policies were developed by patients and transplant professionals to ensure fair and equitable distribution of organs. There are no criteria based on gender, religion, celebrity status, or financial status. The organ is offered to the transplant team of the first person on the list. The transplant surgeon then determines if that person is appropriate for that particular organ, and if so, the transplant takes place. If not, the organ is offered to the next person on the list.

OPOs are the link between organ donors and recipients. They are responsible for coordinating the recovery of organs, ensuring that there is informed consent, managing the clinical care of the donor once consent is obtained, ensuring the viability of the donated organs until transplant, and transporting the organ to the transplant team. They also provide follow-up information to the donor family and hospital staff. Pediatric transplant programs are smaller than adult programs, because fewer children require transplantation, and they must offer special expertise in children's health care (eg, critical care, dialysis, and interventional radiology). Pediatric transplantations should be per-

formed in only the most experienced of institutions.

The family should be involved in every aspect of transplantation. There are unique consequences of transplantation in childhood that require ongoing evaluation and care besides the functioning of the transplanted organ. Special attention must be given to growth and developmental issues to ensure an optimal neurodevelopmental outcome.<sup>22–24</sup> Some considerations for the medical team caring for the pediatric organ recipient include support (emotional and spiritual) for the recipient, other siblings (eg, social aspects relating to their care), and parents or guardians (eg, maintaining employment status) and the availability of pediatric subspecialty support (critical care, dialysis, anesthesia, interventional radiology, etc).<sup>25,26</sup> Children are much harder to relocate to a transplant center for care, because their families must accompany them and siblings must be cared for at the same time. Involvement of the child's primary care physician and local subspecialist can be beneficial in providing follow-up visits and laboratory monitoring where these capabilities exist.<sup>26</sup> This decreases transportation costs and improves patient access to medical intervention. Keeping the family unit intact reduces stress on the family and improves the outcome for the child.

## ETHICAL ISSUES

There are numerous ethical issues involved in the area of organ transplantation. Three general topics are deciding when human beings are dead, deciding when it is ethical to procure organs, and deciding how to allocate organs once they are procured.<sup>27</sup> Additional questions that are raised include: Who should pay for transplantation? Is it ever appropriate to pay for organs? Is transplantation worth the

tremendous cost? Are the benefits justified for all conditions? Is the distribution system as fair as it can be? Should we allow second transplants? It is not the purpose of this policy statement to answer those questions but to raise awareness of them. Donation and procurement of vital organs after cardiac death is ethical, provided informed consent is obtained ahead of time. Organ procurement must not cause death, and death must precede procurement of unpaired organs or both paired organs. Death must be certified by using standardized, objective, and auditable criteria, and death determination must follow state law. All decisions about children are made by parents or guardians on the basis of the best interests of minor children and not on the basis of preservation of patient autonomy per se. It is reasonable for any child for whom a do-not-resuscitate or withdrawal-of-care decision is made in the course of management, or any child who has a nonneurologic death, to be considered a DCD candidate. Unless parents or guardians initiate donation conversations first, discussions regarding donation should occur only after the decision to withdraw support or terminate care has been established. The medical and forensic investigation of the death of a child attributable to trauma (unintentional or resulting from abuse), sudden infant death syndrome, or poisonings presents unique issues related to organ procurement. Close cooperation between the forensic system, transplant team, treating physicians, and OPO facilitates evaluation, guidance, and successful organ procurement in most cases. Cooperation ensures that evidence will not be destroyed and that any injuries noted during organ recovery will be documented and reported. The surgeon also has the responsibility to testify to the condition of the organs at the time of recovery. Some medical examiners

believe that individuals who died as a result of abuse should not be organ donors. However, if protocols are developed through which the historical data, surgical and autopsy findings, and laboratory studies are cooperatively examined, most individuals whose death requires investigation can be donors.<sup>28–30</sup> The National Association of Medical Examiners supports organ donation and is working to achieve zero medical examiner denials.<sup>11</sup>

### **FAMILY SUPPORT**

The American Academy of Pediatrics supports the key role of OPO professionals to provide family support during the donation process and in long-term follow-up of the donor family. The success of these efforts is an integral part of increasing organ donation within the local community. In addition to OPOs, the broader medical community must also provide support to the donor family. This includes nurses, clergy, pediatricians and family physicians, child life specialists, and social workers. Involvement of the child's primary care physician and treating subspecialist during organ procurement and transplantation can be beneficial in bedside management, discussion of complex or unusual diseases, and addressing broader medical issues with the donor family. Education of the primary care pediatrician and other health care professionals about approaching the emotional and physical health of the donor's family can be provided by the OPOs. Sensitivity to the needs, beliefs, and desires of each individual family is an important aspect of organ donation, and these family issues must be considered in each circumstance. Each local medical community must evaluate its resources and have procedures in place to support the family during and after the death of a child. The primary care physician is an integral

part of the care of the family and should be involved in support and follow-up of the donor family. In addition to family support, the staff at the local medical center should also receive training in dealing with the death of a child, including confidentiality and religious, cultural, and ethical issues. Hospital ethics committees are beneficial in the development of staff support and for discussion of difficult cases.<sup>31,32</sup>

### **FINANCIAL ISSUES**

The cost of organ donation is borne entirely by the OPO. Transplant costs are the responsibility of the recipient. Organ transplantation is one of the most resource-intensive and expensive therapies available to children. The costs are higher for children because of a longer expected life span after transplantation and loss of work for parents or guardians.

Despite these increased costs, the significant benefits of organ and tissue transplantation should outweigh financial concerns.

Payment for organ transplantation and subsequent follow-up care may be covered by employer and individual insurance policies. However, the coverage of certain organ transplants, second transplants, and long-term care is variable, and most policies have a lifetime maximum amount or "cap."<sup>33</sup> Once this amount has been reached, the insurance company has no obligation to pay for additional benefits. The amount of the cap varies greatly and may apply to just 1 procedure or to all procedures and treatments combined. The ongoing cost of transplantation plus ongoing long-term care may exceed the cap. Improved long-term survival in younger transplant recipients places them at high risk of reaching this cap. Medicaid rules vary from state to state, but most transplant procedures are now included. Because

publicly funded programs such as Medicaid, the State Children's Health Insurance Program, TRICARE, and others are insurers of a large segment of the pediatric population, transplantation financial issues must be addressed by state and federally funded health care programs.

## PUBLIC AWARENESS

Because the death of a child is often unforeseen, many families have not considered the possibility of organ donation. Pediatricians, children's advocacy groups, and institutions that care for children need to increase awareness of the need for organs with the same enthusiasm with which blood donations and immunization programs are promoted, through the use of posters in waiting rooms, handouts, and other public campaigns. Educational programs have begun with a classroom program titled "Decision: Donation," developed as a part of the US Department Health and Human Services Gift of Life Donation Initiative.<sup>34</sup> Options also exist for the promotion of living donation and bone marrow transplantation. An opportunity to discuss these options within the context of anticipatory guidance during adolescent visits might arise when reviewing the risks of driving.<sup>35</sup> This interaction would better prepare the adolescent for future decisions that he or she may have to make regarding family members and serve to educate the parents of their own organ-donation options. Organ donation is a decision made by families, not by physicians. Every family should be given the opportunity to allow their loved one to become an organ donor. Organ donation should be an option for any family with a loved one for whom end-of-life issues are being discussed.

## RECOMMENDATIONS

1. Pediatricians at local, regional, and national levels should promote the awareness for increased organ donation and support regional transplant programs.
2. Organ donation is an integral part of end-of-life care that provides families with a final decision to make concerning a loved one. Every family should be given the opportunity for organ donation if it is medically appropriate, and it should be the expectation that the family will be approached in a professional, compassionate manner. The decision to donate is one made by the family, not by physicians.
3. Accurate and timely declaration of neurologic death is essential to ensure that viable organs are not lost because of a delay in declaration of death.
4. DCD is a reasonable way to increase the number of organs recovered for pediatric transplantation, especially much-needed livers and kidneys.
5. Timely referral to OPOs can increase organ-donation rates by providing active communication with the health care team and the OPO. Timely notification decreases the likeliness of a rushed approach to donation, which enhances the chances of the family agreeing to organ donation. Collaboration with physicians, the health care team, and the OPO is critical to ensure that every family is provided the opportunity to discuss organ donation during end-of-life discussions.
6. The consent procedure for organ donation should be handled by a trained professional, and the death notification and consent for organ-donation processes should be separated or "decoupled."
7. Education of staff should include medical, ethical, social, cultural, and religious issues related to the potential donor and recipient families.
8. Programs for support of donor families should be in place and coordinated with the child's primary care physician.
9. The treating physician should continue to be involved in cooperative medical decision-making and support of the family after the determination of brain death and cardiac death in the patient who has become an organ donor. Care of the pediatric donor is a natural extension of care for a critically ill or injured child and the child's family. Involvement of pediatric critical care specialists as early as possible can increase organ availability and improve the quality of organs recovered for transplantation.
10. Protocols should be developed that allow cooperative examination of evidence and injuries so that organ donation can successfully proceed in cases in which forensic investigation is required.
11. The US Department of Health and Human Services and the medical community must closely examine all transplant and organ-donation regulations and work to ensure that children are fairly served by their policies.
12. An organ-distribution system should recognize the following:
  - Health care for children who need transplantation is best provided in centers of excellence by a health care system that provides medical care delivered by pediatricians, pediatric medical subspecialists, and surgical specialists with expertise in pediatric organ transplantation.
  - Issues related to relocation of the child and family to a transplant center for care, transpor-

tation, and family support must be addressed at all centers that provide transplantations for children.

13. Adequate financial resources and payment for pediatric organ transplantation and lifetime follow-up care must be available.
14. Pediatricians should be informed of the possibility of transplantation for certain patients, be educated about the process of transplantation, be familiar with the transplant center in their region, and be advocates for their patients and their families in the transplant-listing process.

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## Pediatric Organ Donation and Transplantation

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