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American Academy of Pediatrics Policy Statements on Bioethics: Summaries and Commentaries: Part 2

Mark R. Mercurio, Marilyn A. Maxwell, Brenda Jean Mears, Lainie Friedman Ross
and Tomas J. Silber

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American Academy of Pediatrics Policy Statements on Bioethics: Summaries and Commentaries: Part 2

Mark R. Mercurio, MD,
MA,* Marilyn A. Maxwell,
MD,* Brenda Jean Mears,
MD, MS,* Lainie Friedman
Ross, MD, PhD,* Tomas J.
Silber, MD, MAAS*

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Drs Mercurio, Maxwell,
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and Silber did not
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Introduction

The American Academy of Pediatrics (AAP) has a strong and longstanding interest in the field of bioethics and periodically publishes policy statements pertaining to specific ethical questions relevant to pediatrics. The subjects addressed cover a wide range of topics, from parental refusal of immunization to the care of critically ill children. These policies are authored initially by the AAP's Committee on Bioethics and undergo extensive internal review by other committees prior to publication.

This article is the second in a series of three intended to familiarize readers with many of the AAP policies currently in place that address issues in bioethics. In this series, 16 policies published by the AAP are summarized, each followed by a brief commentary. The commentaries are intended to address, at least on a cursory level, some of the ethical principles underlying the policies. Some briefly point out possible alternative viewpoints.

The policies referenced in this article represent the efforts of various committees and committee members over the years. Each of the summaries presented here, as well as the commentaries that follow, represents the work of an individual serving on the Executive Committee of the Section on Bioethics, as indicated at the beginning of each summary. Understandably, some of the wording of these summaries is taken directly from the published policies. When quotations are used within a summary and not referenced, it can be assumed that the quote is taken directly from the policy being summarized. For ease of use, the references for each policy are provided with each individual summary and commentary.

Policies Reviewed

Part 1 of this series reviews:

1. Informed Consent, Parental Permission, and Assent in Pediatric Practice
2. Religious Objections to Medical Care
3. Responding to Parental Refusals of Immunization of Children
4. Sterilization of Minors With Developmental Disabilities
5. Human Embryo Research

Part 2 of this series reviews:

6. Guidelines on Forgoing Life-sustaining Medical Treatment
7. Forgoing Life-sustaining Medical Treatment in Abused Children
8. Do-Not-Resuscitate Orders for Pediatric Patients Who Require Anesthesia and Surgery
9. Do-Not-Resuscitate Orders in Schools
10. Ethical Issues With Genetic Testing in Pediatrics
11. Ethics and Care of Critically Ill Infants and Children

Part 3 of this series reviews:

12. Female Genital Mutilation
13. Appropriate Boundaries in the Pediatrician-Family-Patient Relationship
14. Infants With Anencephaly as Organ Sources: Ethical Considerations
15. Palliative Care for Children
16. Institutional Ethics Committees

Guidelines on Forgoing Life-sustaining Medical Treatment

Committee on Bioethics. Guidelines on forgoing life-sustaining medical treatment. *Pediatrics*. 1994;93:532-536. Available at: <http://aappolicy.aappublications.org/cgi/>

*On behalf of the American Academy of Pediatrics Section on Bioethics.

content/abstract/pediatrics;93/3/532.pdf. Reaffirmed January 2004. Summary and comment by Mark R. Mercurio, MD, MA.

Summary of Policy Statement

“Life-sustaining medical treatment” (LSMT) refers to any intervention that could prolong the life of the patient, including but not limited to mechanical ventilation, dialysis, and artificial nutrition and hydration. “Forgo” in the context of these guidelines is meant to encompass withholding (failing to initiate) or withdrawing a therapy. The guidelines acknowledge that there is no ethical or legal distinction between not instituting a treatment and withdrawing it. That is, it is equally acceptable to try a treatment for a while and then withdraw it and to refrain from initiating that same treatment. Either decision might be acceptable in certain circumstances and should be based primarily on the relative benefits and burdens to the patient. Those benefits and burdens usually are assessed in light of the values of the patient and the patient’s family. It is acknowledged that individuals may value benefits differently and that families should be given wide latitude:

“Our social system generally grants patients and families wide discretion in making their own decisions about health care and continuing, limiting, declining, or discontinuing treatment, whether life-sustaining or otherwise. Medical professionals should seek to override family wishes only when those views clearly conflict with the interests of the child.”

The guidelines emphasize the following points:

1. Physicians have an obligation to provide decision-makers (generally the parents) with relevant information regarding risks and benefits of available options and to provide a specific recommendation, rather than simply “offer a menu of choices.”
2. Families should be given adequate time to consider the options because they may reconsider as events gradually unfold or become clearer to them. “Decision-making should be treated as a process, rather than an event.”
3. A physician cannot be compelled by patients or families to provide any treatment he or she feels is unlikely to benefit the patient. Hospitals should have policies addressing disagreements that persist after all efforts at communication and collaborative decision-making have failed.
4. Many pediatric patients, such as emancipated minors and some “mature minors” (often judged to be ≥ 14 years old) generally should be viewed as having decision-making capacity for their care. All

children should have the opportunity “to participate in decisions about LSMT to whatever extent their abilities allow.”

5. Decisions for infants and young children should be based on the best interest standard, which dictates a choice based on the relative benefits and burdens of the proposed treatment to the child. The Committee describes potential benefits as follows:

“The benefits may include prolongation of life (understanding that the continuation of biologic existence without consciousness may not be a benefit); improved quality of life after the LSMT has been applied (including reduction of pain or disability); and ‘increased physical pleasure, emotional enjoyment, and intellectual satisfaction.’ ” (1)

Comment

It is widely agreed that, as the policy states, there is no significant ethical difference between withholding and withdrawing an LSMT. Nevertheless, many clinicians have observed a psychological difference in that it often is far more difficult for parents to agree to remove LSMT, such as mechanical ventilation or intravenous nutrition/hydration, than it is to agree not to initiate it.

The foundation of this guideline is the patient’s best interest standard, which states that decisions should be based on an assessment of the benefits and burdens of the proposed treatment. Of course, that assessment often is subjective, with the outcome of the analysis ultimately being a value judgment. Whether the benefits of ongoing LSMT to the patient outweigh the burdens frequently is a matter of opinion. The guidelines state that the values (and, hence, the opinion) of the family generally should prevail, rather than the values of the physician, with one notable exception: “Medical professionals should seek to override family wishes only when those views *clearly* conflict with the interests of the child.” The word “clearly,” perhaps, is the most consequential in the guideline.

An ethical gray zone may have various definitions, but in this case, it is useful to think of it in terms of the child’s best interest. The ethical gray zone might be thought of as the area wherein the best interest of the child cannot be discerned easily. In some cases, the parents’ wishes regarding LSMT clearly (in the opinion of the clinicians) are consistent with the child’s best interests, and no conflict exists. In other cases, parental wishes clearly (again, in the opinion of the clinicians) are opposed to the child’s best interests, and the guidelines rightly advise that steps be taken to override parental wishes. Within the gray zone, the physician might be uncomfortable

with the parental choice and, perhaps, even recommend against it, but does not feel that his or her choice *clearly* opposes the best interests of the child. In such a case, the guidelines do not advocate overriding parental decisions. Only when it seems to the clinicians that the parental wishes are *clearly* opposed to the child's interests should they be overridden. The location of the borders of the gray zone, for any given physician, essentially is determined by the degree of certainty (or clarity) he or she feels about the child's best interest. Within the ethical gray zone, where the best interests of the child seem unclear, the values and judgment of the parents generally should hold sway.

In the case of LSMT, adherence to these guidelines might result in a child being kept alive because of parental request, despite the misgivings or even the frank opposite recommendation of the physician. The physician might be concerned about the pain of the ongoing course or the potential burden of severe disability should the child survive, but be uncertain whether the burdens outweigh the benefit of possible survival. Ongoing patience, communication, and compassion provide the best approach in such a case.

The patient's best interest standard is strictly interpreted to require exclusive consideration of the benefits and burdens *to the patient*. Some have suggested that this is too narrow a view and that it may be legitimate to consider the interests of family members as well. (2) How much weight should be accorded to the interests of the family is a central question in decisions regarding LSMT. Although the AAP guideline generally seems to endorse the patient's best interest standard, it also opens the door to other considerations, at one point stating that physicians and families should include "the interests of others, such as family members and loved ones," in decisions about LSMT.

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Forgoing Life-sustaining Medical Treatment in Abused Children

Committee of Child Abuse and Neglect and Committee on Bioethics. Forgoing life-sustaining medical treatment in abused children. *Pediatrics*. 2000;106:1151-1153. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics%3b106/5/1151>. Reaffirmed Oc-

tober 2006. Summary and Comment by Tomas J. Silber, MD, MAAS.

Summary of Policy Statement

In this joint statement, it is affirmed that the decision to forgo LSMT for a critically ill child injured as the result of abuse should be made using the same criteria as those used for any critically ill child. In addition, the parent or guardian of an abused child may be considered to have a conflict of interest when a decision to forgo LSMT risks changing the legal charge faced by a parent, guardian, relative, or acquaintance from assault to manslaughter or homicide. Therefore, the statement recommends that if a physician suspects that a parent or guardian is not acting in a child's best interest, additional review and consultation should be sought in hopes of resolving the conflict. Such consultation includes requesting the appointment of a guardian ad litem, who represents the child's interests regarding LSMT, in all cases in which a parent or guardian may have a conflict of interest. The statement also clearly addresses the issue of the brain-dead child, suggesting that although brain death is a clinical determination based on established criteria, in cases of abuse, "given the likelihood of criminal prosecution, it may be prudent to supplement the clinical determination of brain death with an ancillary test, such as a cerebral flow study." The document ends with five recommendations:

1. Pediatricians, pediatric subspecialists, and pediatric surgeons should be aware of the legal and ethical issues in caring for children who have been seriously injured as a result of abuse.
2. Regardless of the cause, nature, and extent of a child's injuries, the parent(s) or guardian(s) should be involved, as appropriate, in all aspects of the child's care and treated with respect and due consideration for their privacy.
3. Decisions to forgo LSMT for a critically ill child whose injuries are the result of abuse should be made using the same guidelines as those used for any critically ill child.
4. A guardian ad litem for medical decision making should be appointed in all cases of child abuse requiring LSMT in which a parent, guardian, or prosecutor of the alleged abuser may have a conflict of interest.
5. The medical examiner's office should be involved early and before forgoing LSMT. Local procedures for collecting evidence and performing postmortem examinations should be developed to allow for organ and tissue donation.

Comment

This is among the most tragic circumstances that a pediatrician may encounter in his or her practice. Because it is only human to be enraged at the suffering of the most vulnerable at the hands of those who abuse their power, betray, and hurt them, it initially is counterintuitive to accept the advice that decisions to forgo LSMT be based on complete and compassionate communication with the family, “even if one or both parents are suspected of causing the injury.” However, additional reflection on who we are as pediatricians and what our role and obligations are clarifies that we have been granted by society the special mission of providing support for the parents of critically ill children, which includes identifying for them and offering them the possibility of meeting with bereavement counselors, chaplains, or any other professional or group they may need in the midst of this emotional and spiritual crisis.

The document also is on solid footing when it identifies “the best interest of child” as the primary focus when considering whether to forgo LSMT and appropriately advises that when the pediatrician suspects that the parent is not acting in the best interest of the child, an ethics “consult” should follow in hopes of resolving the conflict. Indeed, an ethics consult can be very useful in assuring the hospital administration that reasonable steps were taken before proceeding to a court hearing. The responsibility of the physician does not end when a court appoints a guardian ad litem. Pediatricians need to function as child advocates, continuing to provide input so the guardian ad litem makes an informed decision. Pediatricians need to be aware that prosecutors may not support a decision to forgo LSMT “out of concern that the case against the alleged abuser may be weakened.”

At the end, the thoughtful and systematic approach of the statement comes around to helping us understand that decision-making in the treatment of abused children is no different from the painful dealings with other injured or moribund children—only more so.

Do-Not-Resuscitate Orders for Pediatric Patients Who Require Anesthesia and Surgery

Fallet ME, Deshpande JK, and the Section on Surgery, Section on Anesthesia and Pain Medicine, Committee on Bioethics. Do-not-resuscitate orders for pediatric patients who require anesthesia and surgery. *Pediatrics*. 2004;114:1686–1692. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;114/6/1686>. Summary and Comment by Brenda Jean Mears, MD, MS.

Summary of Policy Statement

This clinical report from 2004 discusses preexisting do-not-resuscitate (DNR) orders for the pediatric patient who undergoes anesthesia and surgery.

DNR orders may be written for a child at the request of the parent when the burdens of resuscitation exceed any expected benefit. Such orders should not preclude the provision of appropriate surgical interventions. Surgical procedures and anesthesia may increase the risk of hemodynamic instability, but arrests in this setting have a higher percentage of successful resuscitation. Honoring the DNR order may allow a potentially reversible death to occur, but a requirement that the order be suspended in the operating room may not be in the best interest of the patient.

“Required reconsideration” specifies that DNR orders be reviewed during the informed consent process. The various components of the surgery are reviewed and the implications of the DNR considered. An older child is included in the discussions when possible and assent obtained. A family may choose to suspend or modify the DNR order intraoperatively. Procedure-directed planning documents decisions on the use of various interventions but lacks flexibility. Goal-directed approaches focus on patient goals, values, and preferences rather than on individual resuscitation procedures. The timing of resuming previous DNR orders should be planned. Documentation of all discussions and communication to all involved in providing care are needed. If the physician cannot comply with the decisions made by the family, transfer of the patient or involvement of other consultants may be necessary. This consideration of options allows care to be individualized to the needs of the child.

Comment

Parents, acting as surrogates for their children, may refuse treatment without implying a choice to hasten the child’s death. (1) Several points bear emphasis. When a DNR order is in place, there still should be the freedom to request beneficial interventions without fear of prolonged resuscitation or unwanted intensive care. (2) Despite the possible risks of an iatrogenic arrest during anesthesia and surgery, it is not always in the best interest of a child to be resuscitated, and a family may refuse resuscitation attempts. Policies requiring the suspension of a DNR order force families to balance the benefits of surgery against the risks of unwanted resuscitation. (3) Procedures commonly used in the operating room may be considered resuscitation in other situations (3). Reconsideration of the DNR order allows a review of therapeutic interventions that might be used and possible

responses to expected and unexpected events as well as the risks and benefits of the surgery and anesthesia. Suspension or modification of the DNR order can be planned and documented for use during the procedure. (2)(3) If a conflict cannot be settled to the satisfaction of the participants, the preference of the family should prevail.

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Do-Not-Resuscitate Orders in Schools

Committee on School Health and Committee on Bioethics. Do-not-resuscitate orders in schools. *Pediatrics*. 2000;105:878–879. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;105/4/878>. Reaffirmed June 2003. Summary and Comment by Marilyn A. Maxwell, MD.

Summary of Policy Statement

This statement addresses the challenging situation of DNR orders in schools. With the advances of medical knowledge and technology, many children who previously would have died are surviving serious conditions. Challenges involved in the care of these children who have continuing life-threatening health problems can be encountered as they reach school age. Public Law 94-142, the Education for All Handicapped Children Act, provides that children who have disabilities or handicaps “have access to education in the least restrictive environment appropriate for their needs.” The risk of dying while attending school is a real possibility for some children who have chronic and terminal conditions. Parents who have chosen no cardiopulmonary resuscitation for their child also may want this decision carried out while the child is at school. In this statement, the committees stress, “a DNR order is not synonymous with abandonment of all medical treatment and does not, of itself, rescind the obligations of the health care team to provide quality care, such as suction, oxygen, and pain medication.”

School officials may have concerns about DNR orders in schools. Such orders possibly could be misinterpreted

by medically untrained staff, which could result in harm to a child. There also is concern that school personnel may not respond to easily reversible situations, such as a mucous plug in a child who has a tracheostomy. Finally, there are concerns that situations not anticipated by a DNR order, such as a child choking on food or being injured, could cause confusion among personnel. All of these issues raise liability concerns. In addition, there is a consideration of the effect on other students exposed to a death at school.

The AAP believes that pediatricians should be involved with these decisions and work with families and school personnel to provide guidance and advice in this area. The goal of working together would be to ensure that a child’s participation in the education process continue for as long as reasonably possible.

Comment

Children who have life-threatening problems are at risk of dying while in school. Parents, after appropriate consultation, may decide on DNR orders and may wish for these orders to be followed at school. From an ethical standpoint, parents could argue that they, along with their child, have a right to have the DNR order followed at school. On the other hand, school officials may be worried about a variety of other issues, some of which may involve liability for the school. In addition, there is a concern about the effect of a death in school on other students, as well as parents of other children not wanting their children exposed to death at school. This last point also could be presented as a rights-based argument.

Avoiding adversarial struggles between school personnel and parents is important. The AAP recommendations in this area are both helpful and practical in attaining common ground for the school and the family. The AAP recommends that pediatricians work with parents of at-risk children as well as with school and nursing personnel, teachers, administrators, and emergency medical service personnel. “Concerted efforts to accommodate all points of view will help avoid confrontation and possible litigation.” More importantly, finding common ground is in the best interest of children at increased risk of dying in school, should the parents desire a DNR order be followed in the school.

Ethical Issues With Genetic Testing in Pediatrics

Committee on Bioethics. Ethical issues with genetic testing in pediatrics. *Pediatrics*. 2001;107:1451–1455. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/6/1451>. Reaffirmed Janu-

ary 2005. Summary and Comment by Lainie Friedman Ross, MD, PhD.

Summary of Policy Statement

In this statement, the Committee on Bioethics seeks to address three areas of genetic testing and screening in children that raise serious ethical issues: 1) newborn screening, 2) carrier screening, and 3) predictive testing for late-onset disorders.

The two primary ethical issues in newborn screening that the statement addresses are: 1) consideration of how to introduce new tests into newborn screening ethically and 2) examination of the current policy of mandatory screening without parental permission. The statement is aligned with the traditional position that as a public health program, newborn screening must provide a clear benefit to the child, a position that currently is being challenged by some patient advocates. (1) The Committee on Bioethics is against mandatory screening because it fails to acknowledge the role of parents in making decisions for their children. The Committee recommends replacing current mandatory screening practices with a program that requires “mandatory offering,” which is consistent with the position of the AAP Committee on Genetics (although some of those committee members wanted to leave the program as mandatory), (2) the AAP Newborn Screening Task Force, (3) and many other ethical analyses of genetic screening programs. (4)(5)

Carrier detection may occur as an incidental finding (eg, during newborn screening for sickle cell disease or cystic fibrosis) or it may be part of a program for providing reproductive information to adolescents and young adults. The latter rarely has been attempted in the United States but has been undertaken internationally. (6)(7) The Committee on Bioethics takes the position that newborns should not be screened for the purpose of determining carrier status because the primary use of such information is reproductive and is irrelevant to the child. However, when carrier information is discovered incidentally, the Committee states that the information should be conveyed to parents. They also argue against routine carrier screening in adolescents on the grounds that adolescents should decide whether they want this reproductive information as adults. Again, these positions are similar to other United States statements. (4)(5)

Finally, the statement addresses the issue of predictive testing for late-onset disorders, supporting the delay of testing until the child “has the capacity to make the choice.” This position is based on the premise that whether the psychological benefits outweigh the risks is

unclear, and the decision to test takes away the child’s right not to know and to make such decisions for him- or herself.

Comment

The position outlined in this statement is mainstream and consistent with many earlier ethics documents about genetic testing and genetic screening. (4)(5) The great expansion of genetic technologies in the past 5 years has not created much of a change in ethical analysis, although it has influenced genetic practice. First, newborn screening has expanded rapidly without appropriate systems in place to ensure that the policy decisions can be re-evaluated. (8)(9) Second, although many argue against predictive testing and screening of children and adolescents for carrier detection and late-onset conditions, empiric data show that such testing is occurring. (10)(11)

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Ethics and Care of Critically Ill Infants and Children

Committee on Bioethics. Ethics and care of critically ill infants and children. *Pediatrics*. 1996;98:149–152.

Available at: <http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;98/1/149>. Reaffirmed June 2003. Summary and Comment by Brenda Jean Mears, MD, MS.

Summary of Policy Statement

Current LSMT can prolong the lives of patients who, in the past, might not have been treated vigorously. The value of LSMT may be uncertain, which elicits the moral question: When is it appropriate to apply LSMT to a critically ill infant or child? Although a critically ill infant or child ultimately may have multiple physical or mental limitations, it is impossible to predict the outcome accurately for any individual.

This policy references the 1984 Child Abuse Amendments. These “Baby Doe rules” resulted from a perception in the early 1980s that beneficial treatment was being denied to infants. Misconceptions about these requirements may have hampered attention to concerns about possible overuse of LSMT. The actual language may permit more discretion than frequently realized. Exceptions to mandated treatment include “permanent unconsciousness,” “futile” treatment, and “virtually futile” therapy that imposes excessive burdens on the infant. A trial of therapy may be necessary to clarify a clinical situation and the pertinent ethical values in the particular situation.

The AAP supports parental involvement in decisions from the earliest possible moment for all children. Parents are presumed to accept responsibility for providing care for their children and should be informed of available options. Informed decisions should be made together by the family and medical personnel, considering both burdens and benefits. Parents may perceive and value these benefits and burdens differently than medical personnel. Only rarely should the involvement of child protective services be necessary.

Comment

This policy has much in common with other AAP and American Medical Association (AMA) policies and statements. The primary consideration should be the “best interests” of the child. (1)(2)(3) Physicians should justify treatments to families, patients, and themselves based on possible benefits and burdens. (1)(2)(3)(4)(5) Parents need to be fully informed as early as possible (1)(2)(3)(4) because different individuals judge the value of benefits and risks differently. (1) Parents are granted wide discretion in decision making, and physicians should use judicial intervention to override parents only when their decisions “clearly conflict” with the child’s interests. (1)

LSMT should be provided “in conformity with current medical, ethical, and legal norms.” (1) Treatment should be individualized and re-evaluated frequently. (2)(3)(4) Withdrawal of LSMT in some settings may be appropriate; one AMA policy supports withdrawal when the risks of pain and suffering are greater than “any potential for joy.” (3)

This policy has created controversy because it may relate to the 1984 Child Abuse Amendments (the Baby Doe rules) and, more recently, to the 2002 Born Alive Act. (6)(7)(8)(9)(10)(11)(12)(13) The “Born Alive Act” defines “human being” to include any infant born alive at any stage of development. (13) Although the AAP Neonatal Resuscitation Program Steering Committee said that no changes in approach are necessary, there has been concern that this definition may “jeopardize the normative ethical practice of offering discretionary palliative care.” (8)(11)(12)(14)

This policy has been said to give support to the Baby Doe rules, be inconsistent with other guidelines, and be responsible for altered standards of care by limiting the ability “to select individualized treatment plans and act in the best interests of infants” (9) and by disregarding parental concerns about pain and suffering. (15) Predictions of outcome are imperfect, but survival alone is not necessarily in a child’s best interest. (6)(16) The definition of child abuse does include failure to provide medically necessary treatment, (15)(17) and court decisions concerning required treatment have varied. A Texas case upheld the right of parents to make decisions to withhold treatment except in an emergency, (6)(9)(18)(19) but a Wisconsin case seemed to require maximal treatment unless there is irreversible coma or dying. (6)(8)

In brief, each case requires careful consideration by the family members and medical and support personnel that possibly involves multiple group meetings prior to the making of acceptable, appropriate decisions.

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Conclusion

The AAP periodically publishes policy statements and guidelines addressing difficult ethical issues that physi-

cians caring for children continue to face. This review is intended to provide readers with an overview of some of those guidelines and possibly stimulate additional thought and dialogue within the profession. It is presented by the AAP Section on Bioethics as part of its mission to foster education in this area among pediatricians. As the commentaries suggest, there may not be unanimity about the positions taken, and that is important to recognize. The full text of each policy, as well as other relevant references and information, can be found on the web site for the Section on Bioethics at <http://www.aap.org/sections/bioethics>.

The Section on Bioethics serves primarily an educational role within the AAP and beyond. They organize educational forums in bioethics at the annual AAP National Conference and Exhibition, publish a newsletter that includes original articles in the area of bioethics, and carry out other educational efforts intended primarily for pediatricians. In addition, they provide input to the Board of Directors and other committees regarding proposed policy statements and guidelines. Membership in the Section is open to all AAP Fellows who have an interest in bioethics. Affiliate membership also is available to physicians and other health professionals not eligible for AAP membership.

This is the second in a series of three articles. Part 1 appeared in the January 2008 online-only issue of *Pediatrics in Review*, and Part 3 will appear in the May issue.

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American Academy of Pediatrics Policy Statements on Bioethics: Summaries and Commentaries: Part 2

Mark R. Mercurio, Marilyn A. Maxwell, Brenda Jean Mears, Lainie Friedman Ross
and Tomas J. Silber

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