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**Declaration**

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# İSTANBUL DECLARATION ON ETHICS IN PERINATAL MEDICINE

***JOINT COMMITTEE BY EUROPEAN ASSOCIATION OF PERINATAL MEDICINE***
***AND WORLD ASSOCIATION OF PERINATAL MEDICINE***

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## İSTANBUL DECLARATION ON ETHICS IN PERINATAL MEDICINE

### Foreword

Medicine is a healing art and a science, in which communication between the physician and the patient with appropriate informed consent is essential. Despite cultural, social, national, and legal differences, the importance of ethical conduct and continual review of ethical standards is universal in the profession of perinatal medicine. Ethics, which has roots in philosophy, is an essential component of perinatal medicine and addresses the questions, “what is right” and “what we ought to do” in particular clinical circumstances. These questions should be answered on the basis of relevant clinical ethical concepts. These questions should also be addressed on the basis of applicable law, provided it meets international standards of justice and human rights. The General Assembly of the European Association of Perinatal Medicine approves the following **GENERAL ETHICAL CONSIDERATIONS.**

## I. Ethical Reasoning

Scientific reasoning is based on the best available evidence. Ethical reasoning is based on arguments, i.e., giving reasons that appeal to core ethical concepts and identifying why those reasons support a judgment of what should be done in a particular clinical case. There is general agreement in global medical ethics that ethical reasoning should appeal to the following clinical ethical concepts.

 Beneficence is the ethical principle that requires physicians to seek a greater balance of clinical benefits over clinical harms for the patient.

 Respect for autonomy is the ethical principle that requires physicians to elicit the adult, competent patient's informed decisions about clinical management and implement those decisions unless there is a compelling beneficence-based objection to doing so.

 Being a fiduciary requires the physician to protect and promote the interests of the patient and to do so in a conscientious and trustworthy manner.

 Justice is an ethical principle that requires fairness in the allocation of limited resources. Procedural justice requires that the interests of all affected individuals be identified and taken into account. Substantive justice requires that the interests of individuals be satisfied fairly, especially by preventing exploitation.

 Rights are claims against others to be treated in specified ways. Human rights originate in human dignity. As such, human rights are not dependent on any political system and all political systems should respect human rights. Otherwise, they are unjust.

## II. The Application of Ethical Reasoning to Perinatal Medicine

In medical ethics to be a patient means that a human being is presented to a physician and there exist clinical interventions that are reliably expected to result in net clinical benefit for that human being. The relationship between a pregnant woman and fetus is the most intimate in all human experience. Therefore the interests of both should be considered in applying ethical reasoning to perinatal medicine.

In perinatal medicine there are potentially three patients: the pregnant woman, the fetus, and the neonate. Perinatal physicians have an ethical obligation protect and promote the health-related and other interests of the pregnant, fetal, and neonatal patients. Two ethical concepts support this obligation. The first is the physician's clinical perspective on the patient's interests, shaped by evidence-based reasoning, which is expressed by the ethical principles of beneficence and the physician as fiduciary. The second is the pregnant patient's perspective on her interests, shaped by her values and beliefs, which is expressed by the ethical principle of respect for autonomy.

Justice is a global ethical principle that requires each individual be rendered what is due to him or her when resources are limited. Justice is usually understood to mean that the distribution of limited resources should be fair. The interests of all affected individuals should be taken into account, which is required by procedural justice. To the extent possible, the interests of individuals should be satisfied fairly, which is required by substantive justice. A major consideration in substantive justice is preventing and ameliorating exploitation. Exploitation occurs when vulnerable individuals are denied basic human rights, including especially the human rights to health and to health care. A just healthcare policy for perinatal medicine will prevent exploitation of fetal, neonatal, and pregnant patients by ensuring access for these vulnerable to appropriate perinatal medical services.

## III. Pregnant Women, Neonates, and Fetuses as Patients in Perinatal Medical Ethics

 **The Pregnant Woman:** Both the physician's and the patient's perspectives apply to the pregnant patient. Perinatalogists bring to obstetrical care an evidence-based fund of knowledge concerning the diagnosis and management of pregnancy. The pregnant woman brings her own values and beliefs. Perinatal physicians therefore have both beneficence-based and autonomy-based obligations to the pregnant patient

 **The Neonate:** The physician's clinical perspective applies to the clinical management of neonatal patients. The main aim is the healthy growth and development of the neonate. The physician's standpoint is important, because, while neonates exhibit distinct personalities and behavioral repertoires, they are not yet developmentally capable of having their own values and beliefs, i.e., exercising autonomy. In some situations, the newborn must be protected from the family's attitudes. The relationship of parents to a neonate who is a patient is that of a fiduciary, i.e., they have the responsibility to protect and promote the health-related and other interests of their child during the informed consent process. Perinatal physicians and parents therefore have parallel beneficence-based and fiduciary obligations to the neonatal patient.

 **The Fetus:** The application of the physician's clinical perspective to the fetus is complex. The concept of autonomy does not apply to the fetus, because it is developmentally incapable of having values and beliefs. The previable fetus is a patient when the pregnant woman confers this status on it, something that she should be free to do according to her own values and beliefs without bias or interference from others. The viable fetus is a patient in virtue of its ability to survive ex utero albeit with full technological support. Because access to the fetal patient is in all cases through the pregnant woman's body, her perspective as a patient must be taken into account. While she has beneficence-based obligations to the fetal patient, from her own perspective she can set reasonable limits on the risks that she should be willing to take for the sake of the fetal patient. The perinatal physician therefore has beneficence-based and fiduciary obligations to the fetal patient that, in all cases, must be balanced carefully against the perinatal physician's beneficence-based, fiduciary, and autonomy-based obligations to the pregnant patient. This balancing should guide and coordinate perinatalogists, neonatologists, and other healthcare specialists in all cases. The unique psychosocial aspects of each case should also be taken into account.

**Table 1: Ethical Obligations of Perinatal Physicians to the Pregnant, Fetal, and Neonatal Patient**

| | Beneficence-Based Obligations to the Patient | Autonomy-Based Obligations to the Patient | Beneficence-Based Obligations to the other Patient in a Pregnancy |
|---|---|---|---|
| Pregnant Patient | + | + | + |
| Fetal Patient | + | - | + |
| Neonatal Patient | + | - | - |

## IV. Genetic Testing, Counseling, and Research

Research on the genetic bases of disease is rapidly increasing. Genetic testing, counseling, and research shall be mindful of the fact that the implications of genetic information are not limited to the individual from whom it was obtained and that its disclosure can have negative and disruptive effects on the families and communities of the individuals concerned. The ethics of genetic testing, counseling, and research is guided by respect for the pregnant woman's autonomy.

Perinatologists should refer patients only to facilities for diagnostic genetic testing when that facility has demonstrated satisfactory quality assurance and procedures for such testing and maintaining the confidentiality of results

Counseling pregnant patients about the possibility of genetic testing should be non-directive. This alternative should be offered, its nature, benefits, risks, and limits explained, and the pregnant patient should be assured that it is entirely her choice to accept or reject genetic testing of her pregnancy. This is true for both current invasive genetic testing and new forms of non-invasive testing that may become available in the future.

Counseling about the results of genetic testing should also be non-directive. When a genetic anomaly is diagnosed in the fetus, the pregnant woman's first decision concerns continuation of her pregnancy. The alternatives of continuing pregnancy and terminating pregnancy should both be offered without the perinatalologist or genetic counselor making any recommendation about which alternative the pregnant should choose.

If the pregnant patient elects to terminate her pregnancy, referral should be made to a colleague or clinic who is competent and willing to provide safe and effective termination of pregnancy.

If the pregnant patient elects to continue her pregnancy, counseling should be directive about subsequent perinatal management for maternal, fetal, and neonatal benefit. Counseling should be non-directive about the pregnant woman's participation in research on fetal or neonatal interventions, including new forms of genetic intervention that might be developed in the future.

Any genetic information about a pregnant, neonatal, or fetal patient should be strictly protected as a matter of the professional obligation of confidentiality of the perinatologists.

## V. Social Justice Issues in Perinatal Medicine

Social justice has many ethical implications for health policy related to perinatal medicine. Perinatalogists are especially competent in health care systems to advocate for the human rights to health and health care for pregnant, fetal, and neonatal patients throughout the world. Access to health care is an urgent global ethical concern. Each culture and nation poses distinctive economic, social, geographic, and political barriers of access to health care by pregnant, fetal, and neonatal patients. These barriers can adversely affect the human right to health of perinatal patients. Universal access to health care as a basic human right in all health systems is the remedy. Perinatalogists therefore should identify barriers to access to health care that result in the exploitation of pregnant, fetal, and neonatal patients and advocate for the removal of those barriers, to create universal access to perinatal health care. Societies should provide the resources necessary to meet the beneficence-based needs of all pregnant, fetal, and neonatal patients, as a matter of social justice and respect for human rights.

## VI. Relevant Statements of other International Organizations

 Universal Declaration of Human Rights; WHO, in 10th December 1948
 European Convention for the Protection of Human Rights and Fundamental Freedoms ; 4 November 1950, with its 11 additional protocols, on September, 1953
 European Social Agreement, in October 1961
 19 December 1966, and entered into force on 23 March 1976, The International Covenant on Civil and Political Rights and its Optional Protocols.
 Child Rights, WHO General Assembly, November 1989, action in September 1990
 Madrid Declaration on Ethical Standards for Psychiatric Practice; August 25, 1996 and Yokohama, Japan, in August 2002
World Psychiatric Association Ethics Committee's General Assembly in Hamburg, Germany, on August 8, 1999.
 Helsinki Declaration, 2000 Edinburg version, 2002 Washington and 2004 Tokyo additions
 Strasbourg, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research, in January 2005, previously Oviedo, in April, 1997, additional Protocol to the Convention on Prohibition of Cloning Human Beings

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