

# **Organ Transplant Legislation: From Trade to Donation**

**Right to Health Program  
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## Introduction

Organ transplantation is, without a doubt, one of the most significant achievements in modern medicine. In many cases, it is the only treatment for the late stages of organ failure and chronic heart, liver and kidney disease. Organ transplants continue to give hope to millions of people around the world.

Many countries today engage in organ transplant surgeries, but successful programs in these countries do not necessarily offer an organized method for the procurement of organs from donors of various cultural, religious and economic backgrounds. Rather, a high level of societal awareness particularly among doctors, lawmakers, potential donors and organ recipients is the key to the success of organ transplantation.

Although it is a basic tenet that donation must be the foundation for all organ and tissue transplants, the rarity of organs has given rise to a growing commercial market for organs on the local, regional and international levels. As a result, abuse and exploitation takes place, especially of the poor for the benefit of the rich, and also for the benefit of local or cross-border intermediaries, in what is known as “transplant tourism”. It is considered a flagrant violation of basic human rights, particularly the right to life and the right to health.

The World Health Organization (WHO) has monitored the growing phenomena of transplant tourism, which started to appear in the mid-1990s. Estimates show that it accounts for 10% of all organ transplant practices worldwide.<sup>1</sup> Organ trafficking and transplant tourism continue to expand on the local, regional and international levels despite the absence of comprehensive research and documented statistics surrounding the phenomenon. This situation requires nations and their governments to exert greater efforts to limit this phenomenon through the issuance of legislation criminalizing the organ trade. Local, regional

Experience from countries all over the world demonstrates that commercial trade in this area has evolved from being a market that trades organs to being a market that trades people, whereby the poor and the most vulnerable are being exploited —whether directly or through intermediary transactions.

*World Health Assembly, EB124/15, paragraph 5, report on the meeting of 20 November 2008*

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<sup>1</sup> WHO, “WHO Proposes Global Agenda on Transplantation,” 30 March 2007, <<http://www.who.int/mediacentre/news/releases/2007/pr12/en/index.html>>.

and international bodies must also coordinate efforts to stop the spread of the black market in human organs.<sup>2</sup>

For many years, Egypt has been one of the few countries in the world without legislation criminalizing the organ trade and regulating organ and tissue transplant, particularly from the deceased to the living. Nevertheless, the issue has been the subject of a broad debate amid repeated warnings of “a mafia of organ traffickers,” whose victims are the poor and most vulnerable. Increasingly strong demands have been heard for clear, strict legislation that would regulate the chaos in this critical field in the health sector.

On the other hand, a large proportion of those who urgently need organ transplants in Egypt still have no chance of obtaining the necessary organ because of the high cost of the operation, particularly when performed outside the framework of universal insurance (which covers not only the cost of the transplant itself, but post-op treatment and convalescence as well). In addition, the reliance on living donors as the sole source of organs, as is the case in Egypt, has created a severe shortage of organs due to the small number of donors, who often fear complications as a result of the transplantation. This ultimately deprives others of their rights to life and health, thus encouraging transplant tourism and the exploitation of those who are vulnerable.

It is in this context, that the Egyptian Initiative for Personal Rights (EIPR) submits this position paper to offer a rights-based perspective on organ and tissue transplant policies as a means by which the state can meet its commitments to the human rights to health and life. In this document, the EIPR stresses the urgency of a legislation that will put a stop to organ trafficking and ensure the availability of this type of health care for all individuals as part of a system of universal insurance. The EIPR recommends that all concerned parties put aside the debate on the definition of death and look at the consequences of further delaying the proposed law. Finally, the EIPR urges policymakers to be mindful of the fact that this law will be of no value if the state does not allocate the funds needed to implement it, monitor its application and encourage society to adopt a culture of donation.

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<sup>2</sup> Ibid.

## **I. Organ and Tissue Transplant: The Rights to Health and Life**

International conventions have preserved the right to health as a basic human right, stressing the state's obligation to respect and fulfill this right. The right to health is not limited to the provision of preventive and curative health services, but is rather a commitment on the part of states to the right of every person to enjoy the highest attainable standard of physical and mental health.<sup>3</sup>

Accordingly, General Comment No. 14 on the right to health<sup>4</sup> issued by the UN Committee on Economic, Social and Cultural Rights states that "the realization of the right to health may be pursued through numerous, complementary approaches, such as the formulation of health policies, or the implementation of health programs developed by the World Health Organization (WHO), or the adoption of specific legal instruments."<sup>5</sup>

The right to health is comprised of the following elements:<sup>6</sup> the availability of adequate health services and programs, provided by the state; the accessibility to health services without discrimination, which compels the state to ensure that all segments of society can bear the costs of treatment and services; and finally the health services must be of good quality that is acceptable by the citizens. These elements illustrate the importance of formulating legislation that allows the donation of organs to the needy as one means of guaranteeing their right to health. Such legislation would also enable the poor to obtain organs when they need them without discrimination, thus giving them a better chance to recover if they do require an organ transplant.

Applying the standards set forth by Article 12 of the Convention on Economic, Social and Cultural Rights to the obligations of signatory states allows for the

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<sup>3</sup> Article 12 of the International Convention on Economic, Social and Cultural Rights, 1966. Several other international and regional conventions have also uphold the right to health, including the Universal Declaration of Human Rights (1948), Article 25; the Convention on the Elimination of All Forms of Discrimination Against Women (1979), Articles 11 and 12; Convention on the Rights of the Child (1989), Article 24; and the African Charter on Human and Peoples' Rights (1981), Article 16.

<sup>4</sup> The General Comments are documents issued by the UN treaty monitoring bodies, including the Committee on Economic, Social and Cultural Rights to clarify the articles of the treaties they are monitoring, particularly the commitments and principles incumbent on signatory nations to these treaties.

<sup>5</sup> General Comment No. 14 (2000), UN Committee on Economic, Social and Cultural Rights, paragraph 1.

<sup>6</sup> Ibid.

identification of violations of the right to health. Violations can occur “through the omission or failure of States to take necessary measures arising from legal obligations”<sup>7</sup> or when states do not guarantee equal access to health services. The right to health can also be violated through the direct action of states (i.e., the failure to issue a law regulating organ transplant and prohibiting the trade in organs) or the actions of third parties that are not regulated by the state (i.e., the organ-trafficking mafia). In the latter example, the state is failing to protect the poorest and most vulnerable members of society, who are the main victims of the organ trade. They are easy targets of exploitation because of their material needs and their ignorance of the dangers of transplant operations. Measures, such as passing legislation, are needed to protect those persons whose right to health is being violated by a third party.

The right to life is a non-derogable right that the state cannot suspend even in times of war or national emergency; it cannot be abstained by taking measures that may arbitrarily deprive a person of life. Protecting the right to life also entails much more than this, as indicated by General Comment No. 6 on the right to life issued by the UN Human Rights Committee: “Moreover, the Committee has noted that the right to life has been narrowly interpreted too often. The expression ‘inherent right to life’ cannot properly be understood in a restrictive manner, and the protection of this right requires that States adopt positive measures. In this connection, the Committee considers that it would be desirable for States parties to take all possible measures...to increase life expectancy...”<sup>8</sup> Viewed from this perspective, it is necessary to pass an organ transplant law to give citizens the opportunity to live longer and healthier. It is also important to minimize the risks the most vulnerable face as a result of exploitation by organ traffickers.

The report by the UN Special Rapporteur on the sale of children, child prostitution and child pornography, submitted to the Human Rights Council in March 2006, addressed the issue of the sale of children’s organs, since children are amongst the most vulnerable to exploitation. The Rapporteur noted that states that have signed the optional protocol of the Convention on the Rights of the Child on the sale and exploitation of children, as well as the protocol to prohibit human trafficking (which is a protocol to the Convention Against

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<sup>7</sup> Ibid., paragraph 49.

<sup>8</sup> UN Human Rights Committee, General Comment No. 6 (1982), paragraph 5.

Transnational Organized Crime) are obligated to criminalize organ trafficking.<sup>9</sup> Egypt is a party to both protocols. The Special Rapporteur recommended that states pass legislations regulating organ transplant and donation thus criminalizing and punishing those who traffic in organs, in accordance with the guidelines developed by the WHO. The aim of the legislation is to prohibit “‘transplant tourism,’ in which the medical establishments openly take advantage of the disparities between the situation of the donor and the receiver, with significant risks for both persons involved in the transplant.”<sup>10</sup>

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<sup>9</sup> Report from the Special Rapporteur on the sale of children, child prostitution and child pornography, presented to the Human Rights Council, no. A/HRC/4/31, issued on 26 Dec. 2006, <<http://www2.ohchr.org/english/bodies/hrcouncil/4session/reports.htm>>.

<sup>10</sup> Report of the Special Rapporteur, 2006, paragraph 80.



## **II. International Standards Established by Organizations for Organ and Tissue Transplantation**

Since the transplant of organs from living or deceased donors to patients suffering from organ failure first began, international medical organizations and agencies have been careful to issue resolutions prescribing guidelines for the regulation of professional standards and ethics in this field. They have consistently issued recommendations to regulate practices that violate these principles.

The WHO has condemned organ trafficking on more than one occasion, starting with World Health Assembly (WHA) Resolution 40.13 in 1987. It also drew attention to the failure of efforts to combat trafficking and called on countries to compound their efforts in Resolution 42.5/1989. Resolution 44.25/1991 adopted the first draft of the WHO's guidelines for the transplant of human organs and tissues, which established the standard procedural and ethical framework for these operations. WHA Resolution 44.25 stipulated the need to ban the sale of human organs for the purpose of transplantation.

One of the most significant recommendations issued by the WHA was in its 57th session (Resolution 57.18) in May 2004, in which the organization urged member states to exercise effective supervision on organ transplants and seek out living as well as deceased organ donors. It also urged member states to "take measures to protect the poorest and most vulnerable groups from 'transplant tourism'..."

In 2008, the WHO guidelines on organ and tissue transplantation were revised and adopted by the group's executive council in the meeting held in November 2008. The guidelines recommended acquiring legal consent for the extraction of cells, tissue or organs from corpses and allowed donations from the living as long as professionals provide the necessary care to the donor and quality follow-up. Moreover, the donors should be legally competent and able to weigh the information effectively. Finally, they should be motivated by a real desire to donate their organs, without any coercion. The guidelines stress the need for a genetic, legal or emotional relationship between living donors and recipients. Also, the donation should be accepted knowingly and voluntarily. Minors and incapacitated adults must be protected from donating under duress, and the donation must be made without promise of payment or any other material reward. However, donors may be compensated for reasonable costs incurred, including the loss of income.

The guidelines state that doctors involved in determining death cannot be involved directly or indirectly in organ transplant, extraction or exchange in any shape or form. In addition, they prohibit doctors, medical professionals and insurance companies from involvement in transplant procedures if the organ was obtained by exploiting the donor or the relative of a deceased donor, via coercion or payment. In transplant operations, all safety and quality standards must be observed. Furthermore, donation and transplantation systems must be clear and they must protect the privacy of individuals involved in the process.

Recently, more than 150 representatives of medical organizations and governments, as well as sociologists and legal researchers from 78 states and 20 international organizations met for a summit in Istanbul. The meeting concluded with the Istanbul Declaration of 2 May 2008. The summit was organized by two international organizations active in the field, the International Transplantation Society and the International Society of Nephrology. The recommendations contained in the Istanbul Declaration<sup>11</sup> added significant aspects to the system of international standards. The declaration stressed that human donation of organs at death should be encouraged, by governmental and non-governmental institutions. It emphasized the importance of health and psychological care for living donors, as well as the need to regard their actions as a heroic, life-giving feat. It also stressed the need for living donors to undergo medical and psychological evaluations before and after donation in accordance with international guidelines.

The declaration referred to the importance of non-discrimination in organ transplant procedures with regards to gender, ethnicity, religion or financial status in order to achieve the values of justice and equity. The document also provided a definition of organ trafficking,<sup>12</sup> noting that the traffic in organs and transplant tourism violate the principles of equity, justice and respect for human dignity.

The declaration noted that the cost of organ transplantation should not include any payment for the organ, tissue or cells used. Moreover, costs should be

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<sup>11</sup> To see the document, refer to <<http://www.transplantation-soc.org/istanbul.php>>.

<sup>12</sup> The declaration defines organ trafficking as “the recruitment, transport, transfer, harboring or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving to, or the receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation.”

calculated to incorporate legitimate expenses as part of the treatment of organ recipients.

The declaration considers the establishment of an efficient health system a strategic goal in order to prevent the spread of organ failure, which leads to an increased demand for organs. In addition, it stressed the importance of comprehensive insurance systems that can bear the costs of transplantation operations without out-of-pocket payment requirements, which opens the door to organ trafficking. The declaration also stressed the significance of supporting education and raising awareness programs for health sector workers and citizens. Furthermore, the document also noted the importance of joint regional action to prepare a registry of donors and potential recipients without undermining the national interest of any country.

### **III. Organ and Tissue Transfer, Transplantation and Procurement**

Initially, transplantations were limited to the heart, liver and kidney. However, as medicine and surgery have advanced, more opportunities have emerged for the transplant of other vital organs, such as the pancreas, lungs and various types of tissue transplants. These tissue transplants include corneas, cardiac valves, and skin and bone, of which an estimated 3-5 million take place every year around the world.<sup>13</sup>

Kidney transplantation occupies a special status. Although kidney diseases can be treated with dialysis, it is generally agreed upon that kidney transplants are the most optimal treatment for renal failure, in terms of survival rates, improved quality of life and cost efficiency. Both low and high-income countries are similar in this regard and kidney transplants are the most common type of transplantation, accounting for 50,000 of the 70,000 kidney transplants around the world every year.<sup>14</sup>

The transfer of organs from deceased donors requires a strong institutional structure. First of all, it is necessary to identify those who intend to donate their organ(s) and to obtain their consent or the consent of their loved ones. This is followed by the extraction of the donor's organ and its secure transfer for transplant to the medical team performing the surgery.

Although, worldwide, there is a greater reliance on deceased donors, the procurement of organs from living donors has become inevitable to save the lives of thousands of patients on waiting lists. Thus living donation is a possibility, but it requires the formulation of special guidelines to avoid harm to the donor's health.<sup>15</sup>

The problem currently facing the world is that there is a constant, growing need for a source of alternative organs. Until science finds a way to overcome the obstacles facing organ transplant with non-human tissue, humans, particularly the deceased, will remain the sole source of organs available for transplant. This has made organ transplant a sensitive, difficult endeavor, for it is the only

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<sup>13</sup> Rüdiger von Versen, "Ethics, Access and Safety in Tissue and Organ Transplantation: Issues of Global Concern," WHO document WHO/HTP/EHT/T-2003.1.

<sup>14</sup> WHO, "Human Organ and Tissue Transplantation: Report by the Secretariat," WHO document EB112/5 at [http://www.who.int/ethics/topics/human\\_transplant\\_report/en/index.html](http://www.who.int/ethics/topics/human_transplant_report/en/index.html), 2003.

<sup>15</sup> Ibid.

medical specialty in which the death of one patient is the basic condition for saving the life of another. In turn, it has linked the complicated issue of the definition of death to organ transplantation.

### *How to define death?*

Eliminating the traffic in organs is largely dependent on encouraging donations and fostering a culture of contribution. One of the biggest obstacles facing the passage of a law in Egypt is the controversy over the definition of death. Is a person whose brain stem is dead, considered dead? Or does death entail the total shut down of all bodily organs?

Official documents and reports issued by international medical groups and agencies, such as the WHO and the WHA are free of, or more precisely, intentionally avoid agreeing on a unified, international definition of death. Rather, each country has been left to determine those standards appropriate to, and consistent with, the thoughts and beliefs of its own citizens.

In fact, the current dispute is almost entirely a medical dispute; religion settled the matter long ago. Many Muslim clerics and legal scholars, as well as nearly all legislative and religious jurisprudential agencies, have issued statements declaring the permissibility of organ donation and the transfer of organs from living donors on the conditions that no harm come to the donor and no financial payment is made for the donated organ. These institutions have upheld the principle of donation without compensation in order to benefit the living, but they left the clarification of other important principles, such as the definition of death, to doctors. Sheikh Mahmud Ashur, the former Deputy of al-Azhar and a member of the Islamic Research Council, expressed this stance when he said, “The debate over brain death is a medical, not religious, matter. Religious law sees death as the spirit’s exit from the body and the end of life in the body. As for brain death, no cleric should give an opinion; this is for doctors.”<sup>16</sup> Sheikh Ashur placed the burden of defining death on doctors, adding that they are the real cause of the delay in the law since they cannot agree on the definition.<sup>17</sup>

Many countries have overcome the debates on the definition of death. Thus they managed to issue legislation consistent with international standards by referring the issue to special committees of doctors to decide on the matter.

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<sup>16</sup> Mona Abu al-Nasr, “al-Jadal hawl ta’rif al-mawt yu’arqil qanun zira’at al-a’da’ bi-Misr,” BBC Arabic, 24 Feb. 2008, <[http://news.bbc.co.uk/hi/arabic/world\\_news/newsid\\_7261000/7261958.stm](http://news.bbc.co.uk/hi/arabic/world_news/newsid_7261000/7261958.stm)>.

<sup>17</sup> Ibid.

#### **IV. National Legislation to Regulate Organ Transfer, Transplant and Prevent Organ Trafficking**

Because of the lack of national legislation criminalizing organ trafficking and regulating the donation of organs from the deceased, there is an almost complete reliance on living organ donation in Egypt, without strict supervision. As a result very few transplants are performed due to the shortage of organs. This situation relieves the state of its obligation to provide for such operations on a broad basis and allocate the basic financial resources to support them within a system of comprehensive, universal insurance. Thus, the major problem is that a great number of people who need transplants are without a solution. At the same time, the present situation permits organ trafficking because of the absence of deterrent legal statutes.

To take only one example, an organ transplant law will have an enormous positive impact on the lives of liver patients in Egypt, which has one of the highest rates of hepatitis C in the world. According to the most recent study, the first national survey of citizens aged 15-59, 9.8% of the population has the virus.<sup>18</sup> Chronic hepatic viruses bring increased risk of grave complications, first and foremost, cirrhosis, which can lead to liver failure or cancer. Thus far, there is no treatment for these cases except for liver transplantation, which is only for those able to survive the operation.<sup>19</sup>

From 2002 to 2007, official reports indicated that 430 liver transplants were conducted in Egypt.<sup>20</sup> On 20 March 2007, Minister of Health Hatem al-Gabali announced the first successful liver lobe transplant from a living donor at a government hospital, the Sahel Teaching Hospital in Shubra. According to a news report, the patient fully recovered.<sup>21</sup>

While a liver lobe transplant costs nearly LE 600,000 in private hospitals, (an amount which most Egyptian patients cannot afford) it costs only LE 250,000 at the Sahel Teaching Hospital. For the needy, financial support of LE 50,000-200,000 is offered directly from the Ministry of Health or the Misr bi-Kheir

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<sup>18</sup> El Zanaty and Associates, *Egypt Health and Demographic Survey 2008*, Ministry of Health and Population.

<sup>19</sup> Ahmad Shahin, "Zira'at al-a'da' bayn al-tibb wa-l-qanun wa-l-din," *al-Qahira*, Sept. 2007, pp. 37-8 and 60.

<sup>20</sup> Faruq 'Abd al-Majid, "'Amaliyat zar' kabit jadida bi-mustashfa al-sahil khilal ayyam," *al-Ahram*, 11 April 2007, p. 8.

<sup>21</sup> Egyptian State Information Service, "Minister of Health: Liver Transplant Operations To Be Performed at Sahel Hospital," 23 April 2007.

Program in conjunction with the ministry and Dar al-Ifta', which supports the neediest patients with funds from the alms. The Sahel Hospital also has private funding to supplement the costs of such operations.<sup>22</sup>

Nevertheless, there is a major reliance on charity to fund these operations at the Sahel Hospital, which greatly limits them.<sup>23</sup> Clearly, ameliorating the situation requires the creation of a national program as well as the political will to pass the organ transplant bill and guarantee adequate funding for implementation.

It should also be noted that the health consequences of organ transplantation require lifelong treatment, the costs of which the poor have difficulty meeting.<sup>24</sup> The costs of a transplant operation are not limited to the surgery, but also include post-op treatment and follow-up, as well as drugs that the patient must use for a long time (the cost of which is nearly LE 2,000 per month).<sup>25</sup> The donor might also suffer complications, which is why some countries do not allow living donations and rely on deceased donations.<sup>26</sup> There are no precise numbers on the number of successful transplants carried out by the Sahel Hospital, but it is rumored that 7 out of 19 patients did not survive the transplantation.<sup>27</sup>

At the same time, organ trafficking and transplant tourism are widespread in Egypt, although there are no accurate figures on the scope of the phenomenon, or the number of beneficiaries. Ministry of Health officials admit to the existence of trafficking, carried out with the participation of some medical personnel and treatment facilities.<sup>28</sup> Dr. Hamdi al-Sayyid, the president of the Egyptian Medical Syndicate and the chair of the Health and Environmental Affairs Committee in the People's Assembly, estimates that one-third of liver transplants conducted in Egypt are illegal.<sup>29</sup> The Ministry of Health has intensified inspections of facilities that perform organ transplants in recent months after heavy media coverage of the phenomenon and of a WHO report naming Egypt as a site for the trade in

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<sup>22</sup> "Life Is Not a Luxury," *Egypt Today*, Feb. 2008, vol. 29, no. 2.

<sup>23</sup> Faruq 'Abd al-Majid, "Markaz jadid li-jirahat al-kabid bi-mustashfa al-sahil," *al-Ahram*, 24 June 2008, p. 9.

<sup>24</sup> Hiba Farfali, "Marda zira'at al-kabid fi khatar," *Ruz al-Yusuf*, 17 Aug. 2008, p. 2.

<sup>25</sup> Amal Ibrahim, "Zira'at al-kabid wa hisad al-hashim," *al-Ahram*, 15 Nov. 2007, p. 27.

<sup>26</sup> *Ibid.*

<sup>27</sup> Muhammad Hamdi, "Ijabat min mustashfa al-sahil," *Ruz al-Yusuf*, 20 June 2008, p. 9.

<sup>28</sup> See for example, Hifni Wafi, "Sa'd al-Maghrabi wakil wizarat al-sahha: hunak mafiya munazzama li-tijarat al-a'da' al-bashariya fi Misr," *al-Badil*, 24 Aug. 2008, p. 13.

<sup>29</sup> See the Coalition for Organ-Failure Solutions, <[http://www.cofs.org/Where\\_Egypt.htm](http://www.cofs.org/Where_Egypt.htm)>.

organs.<sup>30</sup> This report shows that 78% of commercial donors in Egypt faced adverse health consequences as a result of the operation due to several factors, including the lack of a comprehensive medical examination of donors prior to the operation to assess their health.<sup>31</sup> A report issued by an international organization that monitors and documents organ trafficking (the Coalition for Organ-Failure Solutions), adds that those who agree to these donations, in return for money, are motivated largely by poverty. Moreover, 78% of them spend the money they receive for the operation in the subsequent five months to pay off debts rather than to improve their health.<sup>32</sup> Finally, research shows that 94% of paid donors regret undergoing the operation.<sup>33</sup>

### ***Legal frameworks regulating donation in the absence of national legislation***

Given the inexcusable lack of legislation, the only legal framework that exists to regulate organ transplantation in Egypt was, until last year, the professional code of ethics and conduct of the Egyptian Medical Syndicate.<sup>34</sup> . In addition, since the code is simply a set of ethical principles endorsed by the syndicate, it naturally does not address criminal liability or civil rights. Moreover, it does not contain deterrent penalties for those in breach of the code.

The professional code of ethics states that the syndicate should be informed of any organ transfer to ensure the integrity of both the donation and the transplant, in accordance with the ethical guidelines contained in the code. No transfer may be performed without the prior consent of a special committee. Articles 49, 50 and 51 of the code, established by Minister of Health decree 238/2003 (5 September 2003), state the following:

*Article 49:* The human organs and tissues transplant operations shall be subject to the moral criteria and guidelines stipulated in the legislation and regulations organizing the foregoing.

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<sup>30</sup> Yosuke Shimazono, "The State of the International Organ Trade: A Provisional Picture Based on Integration of Available Information," *Bulletin of the World Health Organization*, vol. 85, no. 12, Dec. 2007, pp. 901-80, <<http://www.who.int/bulletin/volumes/85/12/06-039370/en>>.

<sup>31</sup> D.A. Budiani-Saberi and F.L. Delmonico, "Organ Trafficking and Transplant Tourism: A Commentary on the Global Realities," *American Journal of Transplantation*, 2008, pp. 925-29.

<sup>32</sup> Shimazono.

<sup>33</sup> Budiani-Saberi and Delmonico.

<sup>34</sup> The code is available on the website of the Egyptian Doctors' Syndicate, <[http://www.ems.org.eg/2\\_4/2\\_4\\_4/2\\_4\\_4.htm](http://www.ems.org.eg/2_4/2_4_4/2_4_4.htm)>.



*Article 50:* It shall be imperative upon the physician prior to carrying out an organ transplant operation, pursuant to the legislation organizing the foregoing, to notify the donor of the medical consequences and the risks to which he may be exposed to as a result of the transplant operation. It is also essential to compile the necessary documents which confirm the donor's knowledge of all the consequences in this matter prior to carrying out the operation.

*Article 51:* It shall be prohibited to trade in the human organs, tissues and cells and human embryos. Under no circumstance shall the physician be allowed to take part in these operations. Otherwise he shall be subject to disciplinary accountability.

The terms "legislation" and "regulations" appear twice in the above-mentioned articles, although there is no Egyptian law that criminalizes organ trafficking and regulates donations from the deceased.

The Minister of Health has announced that until an organ transplant law is issued, no transplantation will be permitted except with the approval of the Minister and the Egyptian Medical Syndicate. To regulate transplantations, Ministerial Decree 70/2009 was issued on 22 February establishing a central registry of organ transplants in the Central Administration of Non-Governmental Treatment Facilities and Licenses. The decree requires medical facilities that perform transplants to submit the relevant documentation on the patient and the donor. It also sets general conditions, such as the need for the donor's informed consent. It also requires donors to sign an affidavit to that effect before a specialized committee established by the decree in order to obtain approval for the transplant. The specialized committee contains an unspecified number of technical and legal experts. The decree specifies that any facility found in violation of the decree faces a one-year closure and medical personnel involved in the violations may have their licenses suspended for one year as well. The decree states that "all private and public hospitals shall be directed to have no interactions with the [facility] during this period, and it shall also be announced in the press that there are to be no interactions with the medical personnel. If the violation is repeated, whether by the facility or the medical personnel, both of their licenses will be revoked."<sup>35</sup>

There are specific objectives in passing legislation that regulates organ transplantation and criminalizes organ trafficking. These include the following: putting an end to the spread of human organ trafficking, which has flourished in

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<sup>35</sup> Minister of Health Decree 70/2009, *Official Gazette*, no. 56, 8 March 2009.

Egypt because of widespread poverty, unemployment, corruption, illiteracy and the absence of regulation; establishing a framework to guarantee the intelligibility and integrity of organ procurement from those who decide, either before or after their death, to donate their organs; and reforming as well as integrating the Egyptian health system to guarantee the basic rights to life and health care in the field of organ transfer and transplant. The Egyptian health system must provide quality health services without discrimination, in such a way that does not undermine citizens' ability to access such services.

## V. Preliminary Observations on the Bill

The drafting of an organ transplant bill has passed through several stages, particularly after it was confirmed that illegal organ trafficking exists on a broad scale in Egypt. The debate over the bill began in the People's Assembly at the end of the 1990s, and it was controversial on the issue of organ transfer from the deceased to the living, the definition of death and the establishment of standards to define it.

In the latest attempt to adopt a law, the Ministry of Health submitted a bill to the People's Assembly in March 2009. The submission of the draft was preceded by another debate on the definition of death, which coincided with the 13th conference of the Islamic Research Council, held on 10-11 March 2009. During the conference Dr. Mohamed Sayyid Tantawi, the Sheikh of al-Azhar, reiterated his approval of both living and deceased donations on the condition that there is no financial compensation involved. Leaving the definition of death to specialists, he said, "What has delayed the bill thus far is the disagreement among doctors on the definition of death."<sup>36</sup> During the conference, Dr. Yusuf al-Qaradawi, the Secretary-General of the Federation of Muslim Scholars, objected to the refusal of some to recognize brain death, saying, "True death, as recognized by doctors around the world, is the death of the brain, and there is no provision in religious law or science that indicates it is the death of the heart."<sup>37</sup> This opinion was also supported by Dr. Essam al-Erian during a workshop organized by the Center for Civil Education in conjunction with the Reform and Development Party (under establishment) on the same day. Dr. al-Erian attended the workshop as a representative of the Egyptian Medical Syndicate.<sup>38</sup>

Although the health committees in both the People's Assembly and Shura Council began to discuss the bill before the end of the last parliamentary session, the debate was not concluded and the bill was postponed to the current session. President Hosni Mubarak declared that the bill was a priority in his speech inaugurating the new session of parliament in November 2009. In the same month, a joint committee from the People's Assembly – comprising members of the Committee for Health and Environmental Affairs and the Committee on Legislative and Parliamentary Affairs - was formed to discuss the bill. In an

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<sup>36</sup> 'Ala' Mustafa, "al-Imam al-akbar: ta'attul al-tashri' mas'uliyat al-atibba'," *al-Ahram*, 11 March 2009, p. 19.

<sup>37</sup> Ibid.

<sup>38</sup> Tamir Abu 'Arab, "Atibba' wa rijal din: qanun naql al-a'da' ta'akhhara kathiran," *al-Dustur*, 11 March 2009, p. 4.

unusual turn of events, the discussants strongly agreed on the importance of passing the bill and expressed a desire to overcome previous disagreements that had obstructed its passage in the past. Finally, in a meeting held on 5 December 2009, headed by Assembly Speaker Fathi Surur and attended by Minister of Health Hatem al-Gabali, the joint committee approved the final draft of the bill and referred it to the Shura Council for its opinion on the matter.<sup>39</sup> Once the Shura Council approves the bill, it will be referred back to the People's Assembly where it will be finalized and voted upon, taking into account the Shura Council's comments. .

The bill submitted by the Ministry of Health in 2009 is an important step towards a legislative framework that meets the aforementioned objectives. The bill prohibits the trafficking of organs and tissue, regulates organ transfer and transplant and protects against human rights violations, particularly the rights to life and health care.

The EIPR supports this legislation as consistent with the principles of human rights, while reiterating the need to take several fundamental measures to make the legislation effective.

The bill consists of 22 articles and creates a legislative framework that meets the general guidelines established by the WHO and other major conventions in accordance with internationally recognized standards.

The text resolves the dispute over the definition of death, leaving the determination to a committee of three specialized doctors working in accordance with standards to be established by the law's implementing regulations. This article offers a wise exit from the long-standing dilemma on the determination of death.

The bill also sets serious deterrent penalties for violations, particularly for organ traffickers. It also addresses a set of vital regulations and conditions needed to regulate the transfer and transplant of organs and to prevent trafficking. For example, it establishes the licensing procedures for centers engaged in organ transfer and transplant as well as the foundation of care for patients with organ failure in order to guarantee they undergo a social and psychological evaluation before they are placed on the organ waiting list. Licensing procedures will also

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<sup>39</sup> Nur 'Ali, "al-Sha'b y uwafiq 'ala qanun naql wa zira'at al-a'da'," *al-Yawm al-sabi'* online, 5 Dec. 2009; 'Imad Fu'ad and Muhammad 'Abd al-Qadir, "Lajnat al-sahha bi-majlis al-sha'b tuwafiq 'ala qanun zar' al-a'da'," *al-Masry al-yom*, 6 Dec. 1009, p. 1.

guarantee follow-up and treatment for patients who undergo transplants. It upholds the principle of the fair distribution of organs obtained from the recently deceased and sets standards for the selection of living donors that are consistent with professional ethics. It also requires written consent from donors with full knowledge of all details of the donation during and after the operation. In short, these provisions provide safeguards and set guidelines consistent with international standards.

## **VI. Basic Steps Needed to Implement the Law**

Despite the positive aspects of the bill, the EIPR believes that the state must take decisive measures to implement the law after its adoption by the People's Assembly. If the real intent of the law is to end organ trafficking and provide an adequate legal framework for organ donation, the EIPR recommends that these measures be established by the implementing regulations. Moreover, these measures must be adopted when executing policies, programs and plans connected to the law, after its passage.

### ***A. Definition of death***

There is a definite (or an urgent) need for a precise, well-written definition of death to be followed by state institutions and facilities that perform organ transplants. However, we believe that drafting this definition is not the legislature's job. Rather, the law must lay the foundation and set safeguards that guarantee the competence, integrity and transparency of the process. Nevertheless, the definition itself requires a committee of specialists, commissioned by the state, which will fully research the issue and agree on a definition to apply to all facilities.

We should not forget that citizens in our country die every day and no one asks whether it is brain death. Each country must establish a technical definition of death and isolate the issue from that of organ transplant.

### ***B. Systems for the transfer and transplant of organs and tissue***

The bill establishes a higher committee, formed by the Minister of Health, to oversee the administration and organization of organ and tissue transplantation. The committee shall classify donated organs and tissue and register potential recipients by tissue, immunity, blood type etc. The committee shall supervise and inspect hospitals and medical centers that perform organ transfers and transplants as well as issue the requisite licenses.

Clear standards that specify the committee's role and how it shall discharge all of its mandates, as stipulated by the law, must be established in order to guarantee impartiality and precision, and to enable the committee to fulfill its duties. This is important since the committee will oversee the selection of those hospitals that are permitted to perform transplants. Furthermore, it should have its own budget and adequate financial resources, proportionate to the sensitivity and difficulty of its tasks.

The existence of an independent committee that offers quality medical services and supervision will pave the way for broad public support. Moreover, the independence of the committee will encourage citizens to adopt a culture of donation and propagate it throughout society. Over the years, the lack of trust in the health system has had a detrimental effect on community contribution and on those who have a sincere desire to donate.

The government has issued several statements recently regarding the submission of a new health insurance bill in the current parliamentary session. Organ transfer and transplant must be included in any new health insurance system. Otherwise, it will remain a luxury available only to the wealthy.

### ***C. Conditions for the transfer and transplant of organs and tissue***

The bill lays out conditions for the transfer of organs from the living to the living, stressing the need to preserve the life of the recipient without undermining the donor's right to life. It also emphasizes the necessity for treatment from serious illness when there are no other adequate options, as long as this does not risk the life of the donor.

This, in particular, requires the establishment of detailed medical guidelines which specify the risks to the donor, the specific clinical conditions that must be met for donation and the physical and psychological follow-up care, to be administered based on internationally recognized standards.

As for donations from the deceased, there must be safeguards to ensure that the higher committee, which oversees transplant and transfer, will act without discriminating among potential recipients. A strong system must be established for monitoring and supervising all aspects of the waiting list for patients requiring transplants. Moreover, if any malpractice is proven, existing penalties for fraud and falsification of official documents should be applied to all those involved.

### ***D. Raising awareness***

The law establishes conditions for transferring organs from the deceased to the living. For example, consent before death is an important precondition for transferring organs. The rules and procedures of this law will be established by the implementing regulations. In any case, it is stipulated that no payment may be involved, that donations from Egyptians to Egyptians must take priority, and that human dignity must be protected when transferring organs.

Although the culture of organ donation is not prevalent in our society, this article did not consider encouraging post-mortem donation or drafting policies to foster a culture of donation at death. Thus, the state must initiate a broad awareness campaign to change attitudes toward death and organ donation. The Special Rapporteur on the sale of children, child prostitution and child pornography has also recommended “educational programs as well as awareness-raising activities” as “essential in the fight against traffic of organs.”<sup>40</sup>

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<sup>40</sup> Report by the Special Rapporteur, 2006, paragraph 86.