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# A Kidney for a Life: Julio's<sup>i</sup> Story

## Julio's World

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Julio de los Reyes looked up from his task of sorting plastic bottles at the well-dressed figure walking among the sorters at the Calajunan dumpsite<sup>ii</sup> in Iloilo City, Panay Island, Philippines. "Sir Mike," as most people called him, had been hanging around for several months, not only talking about how selling a kidney could help families financially, but also how altruistic it could be.

"Yeah, right!" Julio muttered under his breath.

He wasn't born yesterday. And he was not uneducated. He was in his junior year in high school when he had to quit suddenly so that he could work to support his younger brothers and sisters after his

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<sup>i</sup> Julio de los Reyes is a kidney transplant donor/dumpsite worker. A pseudonym is used for the interviewee for his protection and privacy.

<sup>ii</sup> The Calajunan dumpsite is Iloilo City's garbage composting and material recovery facility, where some lower-income individuals work as garbage sorters for a living.

father died of tuberculosis.<sup>iii</sup> So he knew from high school biology what kidneys were for and how important they were. While one can live with just one functioning kidney, life is not the same.

Take his neighbor, Simon, for instance. When Sir Mike told him that he could sell his kidney for 120,000 PhP (USD 2,580),<sup>iv</sup> Simon jumped at the chance. He started telling everyone that this was his hope for a better life — that he would use the money to build a small business and that he would be able to send his four children to school. Where was Simon now? Back at their shanty, barely able to stand. There were complications from the operation; no one knew that he would develop a major infection. His 120,000 PhP (USD 2,580)? All gone from visits to the hospital and the local health center and from the medication he had to take for the infection. Now Simon's wife had to work extra hard to feed him and their four kids. Only one of their children was going to school, and there was never enough money to feed them all.

And take Tatang, the drug-crazed addict who roamed the slums. In his haste to obtain money to buy shabu,<sup>v</sup> he sold his kidney to Sir Mike for only 15,000 PhP (322.58 USD)! Where was Tatang now?

"More than likely six feet under," Julio thought to himself.

He had not seen Tatang around for several weeks now. In his condition, he most likely would have died from the operation, which would be a bonus for Sir Mike; he would have two kidneys instead of one.

Who is this Sir Mike? Is what he is doing even legal? If Sir Mike approaches Julio, should he say yes? Would 120,000 PhP (USD 2580) be worth the sacrifice? That kind of money could indeed be enough for a small business, like a sari-sari store,<sup>vi</sup> for instance. It could buy school supplies and new clothes for the kids as well as milk for the baby. But then again, how long would the money last? What if what happened to Simon happened to him too? How could he work at the dumpsite if he got sick?

## Kidney Transplantation

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Kidney or renal transplantation happens in persons with end-stage renal disease. End stage renal disease usually results from complications of a variety of diseases like chronic kidney disease, malignant hypertension, infection, diabetes mellitus, focal segmental glomerulosclerosis; and genetic causes like polycystic kidney disease, inborn metabolic disorders; as well as autoimmune conditions, like lupus. The majority of patients who undergo a kidney transplant are on dialysis at the time of transplantation.

In most cases, the procedure does not require removal of existing kidneys. In fact, studies have shown that removal of existing kidneys increases the rate of surgical morbidity. Therefore, the transplanted kidney is usually placed in a different location from the original kidney, most often in the iliac fossa, so it is necessary to use a different blood supply. This is usually the renal artery or vein of the donor.

It is attached to the external iliac artery or external iliac vein of the recipient. The procedure approximately takes three hours.<sup>1</sup> **Exhibit 1** shows a diagram of how the recipient kidney is attached.

iii Tuberculosis is a severe microbial infection caused by *Mycobacterium tuberculosis*, a very common infectious disease in the Philippines.

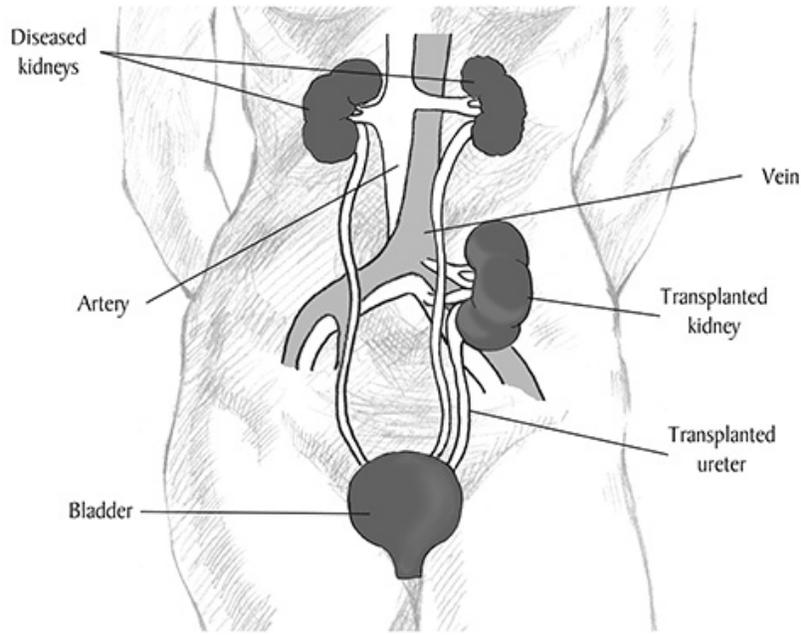
iv The Forex rate of the Philippine Peso (PhP) was approximately 46.50 PhP = 1 U.S. Dollar (USD) as of May 7, 2016.

v Shabu is the slang term for the drug, methamphetamine.

vi A sari-sari store is a local convenience store found in the Philippines. It is usually privately owned and operated and located in the owner's house. These stores are usually found in residential communities.

**Exhibit 1**

Diagram of a Kidney Transplant



Source: Weill Cornell Medical College. "Kidney and Pancreas Transplantation." Accessed 16 May 2016. <<http://www.cornellsurgery.org/patients/services/transplantation/adult-kidney.html>>.

Ten percent of the world's population was affected by chronic kidney disease and of the 2 million people who received treatment for kidney failure, the majority were treated in just five countries — the United States, Japan, Germany, Brazil, and Italy. These five countries represented only 12% of the world population. Only 20% were treated in about 100 developing countries that made up over 50% of the world population.<sup>2</sup> As of 2013, 117,733 organ transplants were reported globally, and 78,952 of these were kidney transplants.<sup>3</sup>

**Kidney Transplant Classifications**

Kidney transplantation may be classified as deceased-donor (formerly known as cadaveric) or living donor transplantation, depending on the source of the donor organ. Living donor transplants are further classified as genetically related (living related) or non-related (living unrelated) transplants, depending on the recipient's biological relationship with the donor.<sup>4</sup>

**Kidney Transplant Requirements for a Donor**

Potential living donors are carefully evaluated both medically and psychologically to ensure that the donor is fit for surgery and has no disease which will bring unnecessary risk for the recipient or the donor. The donor and recipient should also be of the ABO blood group and crossmatch compatible. The psychological aspect is additionally considered to ensure that the donor gives informed consent and is not coerced. In countries where paying for organs is illegal, the authorities may also demand proof that the donation has not resulted from a financial transaction.<sup>5</sup> To avoid complications such as this,

altruistic donation is greatly encouraged, since it does not require any compensation other than hospital expenses.<sup>6</sup>

### **Outcomes for the Donor and the Recipient**

Kidney transplantation is supposed to be a life-extending procedure. Without complications, the recipient may live an additional 10 to 15 years in deceased donor transplants, and an additional 15 to 20 years in living donor transplants.<sup>7</sup> The recipient, however, has to take immunosuppressant drugs to prevent the immune system from rejecting the donor kidney. This is a lifelong maintenance medication. Recipients are also discouraged from consuming grapefruit, pomegranate, and green tea products, since these food products are known to interact with transplant medications.<sup>8</sup> Complications in some cases include transplant rejection, infections, and sepsis due to taking the immunosuppressant drugs, post-transplant lymphoproliferative disorder, electrolyte imbalances, proteinuria, and hypertension.<sup>9</sup> For regular, healthy donors the prognosis is good, provided that they live a healthy lifestyle and avoid substance abuse, contact sports, and high-risk activities. The most common complications are infection and sepsis, which may be acquired from poor post-operative practices, electrolyte imbalances, proteinuria, and hypertension.

## **Julio's Musings and Reflections**

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Julio could not stop thinking about the money. He knew that given the opportunity, he would have good use for it. He never was able to go back to school after he started working; first, as a laborer at a construction site and then, when the building was finished, he started working at the dumpsite. He had worked there ever since. After working his fingers to the bone to support his brothers and sisters, who all eventually dropped out of school when times became more difficult, he met his wife, Remedios, also a worker at the dumpsite. They soon had six mouths to feed. The kind of money that a kidney donation would bring could indeed go a long way, if he spent it wisely. But seeing Simon and Tatang's plight, he felt that something was terribly wrong.

## **Human Organ Trafficking**

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### **Background**

The increasing worldwide demand for kidney donations had triggered a problem of unmatched supply and demand. This had generated a massive global search for possible organ donors. Many people had resorted to medical tourism to secure transplants through legal or illegal means, even though survival rates were quite low.

Trade of human organs is illegal in most countries, but the demands of poverty, particularly in developing countries, make it one of the most pressing global problems today. The problem occurs when people agree to sell their organs and enter into a formal or informal contract to do so; however, once the organ (i.e., kidney) is removed, they are not paid at all, or only a part of the initially agreed upon price (which is often not enough to meet the demands of living without the organ).<sup>10</sup> Globally, it is considered wrong to buy and sell human organs such as kidneys because it would be immoral to make a profit from the commercialization of organs.

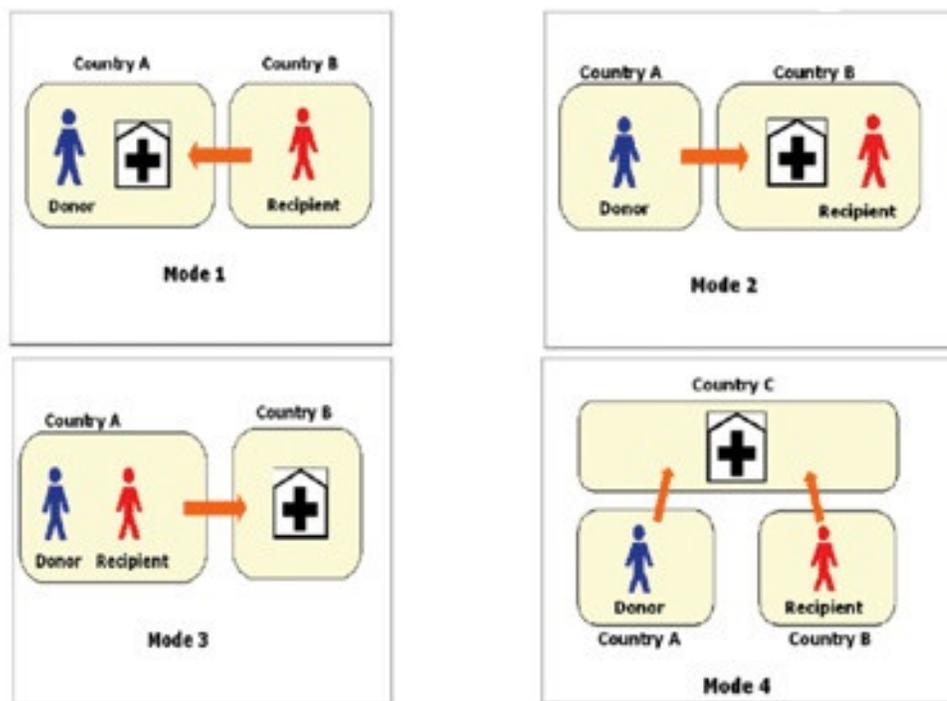
### **The System of Organ Trade**

In developing countries, people are coerced to sell their organs illegally due to immense poverty. Transplant tourism, defined as the purchase of a transplant organ abroad, includes access to an

organ while by-passing laws. Yosuke Shimazono illustrated four modes of transplant tourism. Mode 1 entails a recipient traveling from Country B to Country A where the donor and transplant center are located; Mode 2 entails a donor from Country A traveling to Country B where the recipient and transplant center are located; Mode 3 entails a donor and recipient from Country A traveling to Country B where the transplant center is located; and Mode 4 entails a donor from Country A and a recipient from Country B traveling to Country C where the transplant center is located. These are summarized in **Exhibit 2**.

### Exhibit 2

Modes of International Organ Trade and Organ Trafficking



Source: Budiani-Saberi, D.A. and Delmonico, F.L. "Organ Trafficking and Transplant Tourism: A Commentary on the Global Realities." *American Journal of Transplantation*. 2008;8:925-979. Accessed 16 May 2016. <<http://onlinelibrary.wiley.com/doi/10.1111/j.1600-6143.2008.02200.x/pdf>>.

### Unregulated Kidney Trade and Transplant Tourism

In most countries, access to organ transplantation varies, depending on their economic and healthcare systems. Such situations are determined by the cost of healthcare, availability of transplant services, level of technical expertise, and availability of organs.<sup>11</sup>

The extent of organ sales from commercial living donors was estimated in 2007 to account for 5%-10% of kidney transplants performed annually throughout the world.<sup>12</sup> Based on activity data from 2008 for 104 countries, representing nearly 90% of the worldwide population, it was shown that around 100,800 solid organ transplants were performed worldwide: 69,400 were kidney transplants (46% from living donors).<sup>13</sup>

Because of the increase in demand for organ donors and the shortage of recipient organs, it had been observed since 2004 that patients from developed countries travelled to economically challenged ones to buy organs.<sup>14</sup> **Exhibit 3** shows the number of patients going overseas for transplants.

## Exhibit 3

## Patients Going Overseas for Transplants

Country (Year)	Numbers of Transplants
Malaysia (2004)	<ul style="list-style-type: none"> <li>• 132 renal transplants outside the country (China, India)</li> <li>• 42 renal transplants in Malaysia</li> </ul>
Oman (2003)	<ul style="list-style-type: none"> <li>• 83 living nonrelated renal transplants outside the country (Iran, Pakistan)</li> <li>• 8 renal transplants inside the country</li> </ul>
The Republic of Korea (2004)	<ul style="list-style-type: none"> <li>• 73 overseas transplants in China in 2003; 124 as of the end of 2004</li> </ul>
Saudi Arabia (2006)	<ul style="list-style-type: none"> <li>• 646 renal transplants outside the country</li> <li>• 351 renal transplants inside the country</li> </ul>
Taiwan, China (2005)	<ul style="list-style-type: none"> <li>• 451 transplants in other Chinese areas; 300 for renal transplants; the rest for liver, heart, lung transplants</li> </ul>

Source: Shimazono, Yosuke. "The State of the International Organ Trade: A Provisional Picture Based on Integration of Available Information." *World Health Organization*. 2007: 85:955-962. Accessed 7 May 2016. <[www.who.int/bulletin/volumes/85/12/06-039370.pdf](http://www.who.int/bulletin/volumes/85/12/06-039370.pdf)>.

Developing countries like China, Pakistan, India, and Turkey promoted medical tourism, wherein services such as organ transplants were advertised in attractive package deals for USD 15,000-USD 150,000. Because of this, they had acquired the unsavory reputation of being the world's most popular "kidney bazaars." But there seemed to be a price differential. An African, South Asian, or Chinese kidney was relatively less costly, whereas Turkish or Peruvian ones were several times more expensive.<sup>15</sup> A report listed a number of websites for transplant tourism with pricing of the package deals per country.<sup>16</sup> Most of these websites were soon taken down after the release of international guidelines and regulations on the organ trade. **Exhibit 4** shows the list.

The practice of organ trade was proven in an interview with organ donors and recipients participating in the kidney trade in the Philippines. One organ donor claimed that he was offered 120,000 PhP (USD 2,580) for his kidney, but was paid only 90,000 PhP (USD 1,978) after the operation. According to this source, the "fixer" (middleman) claimed that part of the compensation went toward "processing."<sup>17</sup> A sister of another organ donor claimed that in her brother's haste to acquire drugs (the donor was a drug addict), he agreed to sell his kidney for 15,000 PhP (USD 322).<sup>18</sup>

This is evidence that kidney donors in economically challenged countries were often taken advantage of. Most of these donors barely finished high school, and were not informed of the risks and consequences involved in kidney donation. They also belonged to the lower income bracket, thus often did hard manual labor to support themselves and their families. They had no social safety net or health insurance, were often deep in debt, and usually resided in slum areas with lower standards of living, increasing their risk for complications after the surgery.

Internationally, there are three organizations that address transplant tourism: the World Health Organization (WHO), the Transplantation Society (TTS), and the International Society for Nephrology (ISN).<sup>19</sup> These organizations have released documents and guidelines which prohibit organ trade.

**Appendix A** was drafted and publicized by WHO in 1991. This further gave rise to the World Health Assembly resolution (WHA57.18), which urged member states to protect the poorest and most vulnerable groups from transplant tourism and the organ trade.

## Exhibit 4

## Transplant Tourism Websites Available 21 March 2007

Name of organization, web site	Location of transplantation	Transplant package
BEK-transplant ( <a href="http://www.bek-transplant.com/joomla/index.php">http://www.bek-transplant.com/joomla/index.php</a> )	China	Kidney (US\$ 70 000) Liver (US\$ 120 000) Pancreas (US\$ 110 000) Kidney and pancreas (US\$ 160 000)
China International Transplantation Network Assistance Center ( <a href="http://en.zoukiishoku.com/">http://en.zoukiishoku.com/</a> )	China	Kidney (US\$ 65 000) Liver (US\$ 130 000) Lung (US\$ 150 000) Heart (US\$ 130 000)
Yeson Healthcare Service Network ( <a href="http://yeson.com/index.htm">http://yeson.com/index.htm</a> )	China	Kidney, liver, heart and lung
Aadil Hospital ( <a href="http://www.aadilhospital.com/index.html">http://www.aadilhospital.com/index.html</a> )	Pakistan	Kidney
Masood Hospital ( <a href="http://www.masoodhospital.com/services/surgery/ktp/kidney_transplant.htm">http://www.masoodhospital.com/services/surgery/ktp/kidney_transplant.htm</a> )	Pakistan	Kidney (US\$ 14 000)
Renal Transplant Associates ( <a href="http://www.renaltransplantsurgery.com/index.html">http://www.renaltransplantsurgery.com/index.html</a> )	Pakistan	Kidney [Euro 16 000 (US\$ 20 500)]
Kidney Transplant Associates ( <a href="http://www.kidney.com.pk">http://www.kidney.com.pk</a> )	Pakistan	–
Liver4You ( <a href="http://www.liver4you.org/">http://www.liver4you.org/</a> )	Philippines	Kidney (US\$ 85 000)

Source: Shimazono, Yosuke. "The State of the International Organ Trade: A Provisional Picture Based on Integration of Available Information." *World Health Organization*. 2007: 85:955-962. Accessed 7 May 2016. <[www.who.int/bulletin/volumes/85/12/06-039370.pdf](http://www.who.int/bulletin/volumes/85/12/06-039370.pdf)>.

Major changes in policies and practices had occurred in countries that had previously been centers of organ trafficking and transplant tourism. Among these were Pakistan, India, China, the Philippines, Columbia, and Latin America, where national laws that prohibited or at least regulated the organ trade, were drafted and implemented. The core concept of the legal provisions was self-sufficiency; i.e., the poor countries would not allow organs from living donors to be sold to foreigners, rather they would be provided to their own citizens. Wealthy countries would develop adequate transplant programs, including the use of deceased donation to the maximum extent possible, rather than allow their wealthy, well-insured citizens to purchase a kidney in a country where organs were sold.<sup>20</sup> Despite such steps toward change, the issue still posed a challenge. The organ trade persisted in these countries; thus, the battle continued.

### For Love of a Son

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Julio was roughly interrupted from his reverie when Tomas, his second son came and pulled at his shirt.

"Tay,<sup>vii</sup> it's Manong<sup>viii</sup> Jun ... He's at the hospital. The foreman said that a cement block fell from the building and hit him on the head. They said it's serious."

vii "Tay" is short for "Tatay," which means "Father" in most Filipino dialects

viii "Manong" is the term Ilonggos (locals of Iloilo) use to address their older brothers, male cousins, or other older male relatives. It is originally an Ilokano term which means "older brother," but has been adopted by other regions to address not only real older brothers, but also persons who are a little older as a sign of respect.

Shortly after, Julio stared at the still figure of his son, Jun as if in a daze. He lightly touched Jun's sweating, ashen face and looked around blankly at the six occupied beds of the ward as the weary-looking doctor approached him and asked if he was the father of Jun de los Reyes. The doctor's voice sounded muffled as if belonging to another dimension. The only words which registered after all the medical jargon were "should undergo an operation;" "might never wake up;" "prepare around 500,000-1.2 million PhP (USD 10,989-26,373) for the operation; and "should have a down payment of at least 70,000 to 100,000 PhP (USD 1,538-2,197) to proceed with the operation."

A few hours later, Julio stood by a sari-sari store and asked if they had a pay phone. He took something from his pocket with sweaty, shaking hands. It was the calling card given to him by one of his co-workers who had been talking to Sir Mike.

He thought about his son, who lay in the hospital and could not wake up — the son who, like him, at age 15, had to work at a construction site to help support his family, the son who was his partner in all his hardships, his first born. Jun's doctor said the operation had to be done in 48 hours. Julio stared at the card, and shook his head. His shoulders dropped with resignation. With heavy fingers and with a heavy heart, he punched in Sir Mike's number.

## Appendix A

### 1991 World Health Organization Guiding Principles for Human Organ Transplants

#### Guiding Principle 1

Cells, tissues, organs may be removed from bodies of deceased persons for the purpose of transplantation if: (a) any consent required by law is obtained; and (b) there is no reason to believe that the deceased person objected to such removal.

#### Guiding Principle 2

Physicians determining that a potential donor has died should not be directly involved in cell, tissue, or organ removal from the donor or subsequent transplantation procedures; nor they be responsible for the care of any intended recipient of such cells, tissues, or organs.

#### Guiding Principle 3

Donation from deceased persons should be developed to its maximum therapeutic potential, but adult living persons may donate organs as permitted by domestic regulations. In general living donors should be genetically, legally or emotionally related to their recipients.

Live donations are acceptable when the donor's informed and voluntary consent is obtained, when professional care of donors is ensured and follow-up is well organized, and when selection criteria for donors are scrupulously applied and monitored. Live donors should be informed of the probable risks, benefits and consequences of donation in a complete and understandable fashion; they should be legally competent and capable of weighing the information; and they should be acting willingly, free of any undue influence or coercion.

#### Guiding Principle 4

No cells, tissues or organs should be removed from the body of a living minor for the purpose of transplantation other than narrow exceptions allowed under national law. Specific measures should be in place to protect the minor and, wherever possible the minor's assent should be obtained before donation. What is applicable to minors also applies to any legally incompetent person.

#### Guiding Principle 5

Cells, tissues and organs should only be donated freely, without any monetary payment or other reward of monetary value. Purchasing, or offering to purchase, cells, tissues or organs for transplantation, or their sale by living persons or by the next of kin for deceased persons, should be banned.

The prohibition on sale or purchase of cells, tissues and organs does not preclude reimbursing reasonable and verifiable expenses incurred by the donor, including loss of income, or paying the costs of recovering, processing, preserving and supplying human cells, tissues or organs for transplantation.

#### Guiding Principle 6

Promotion of altruistic donation of human cells, tissues or organs by means of advertisement or public appeal may be undertaken in accordance with domestic regulation. Advertising the need for or availability of cells, tissues or organs, with a view to offering or seeking payment to individuals for their cells, tissues or organs, or, to the next of kin, where the individual is deceased, should be prohibited. Brokering that involves payment to such individuals or to third parties should also be prohibited.

#### Guiding Principle 7

Physicians and other health professionals should not engage in transplantation procedures, and health insurers and other payers should not cover such procedures, if the cells, tissues or organs concerned have been obtained through exploitation or coercion of, or payment to, the donor or the next of kin of a deceased donor.

#### Guiding Principle 8

All health care facilities and professionals involved in cell, tissue or organ procurement and transplantation procedures should be prohibited from receiving any payment that exceeds the justifiable fee for the services rendered.

#### Guiding Principle 9

The allocation of organs, cells and tissues should be guided by clinical criteria and ethical norms, not financial or other considerations. Allocation rules, defined by appropriately constituted committees, should be equitable, externally justified, and transparent.

#### Guiding Principle 10

High-quality, safe and efficacious procedures are essential for donors and recipients alike. The longterm outcomes of cell, tissue and organ donation and transplantation should be assessed for the living donor as well as the recipient in order to document benefit and harm.

The level of safety, efficacy and quality of human cells, tissues and organs for transplantation, as health products of an exceptional nature, must be maintained and optimized on an ongoing basis. This requires implementation of quality systems including traceability and vigilance, with adverse events and reactions reported, both nationally and for exported human products.

Source: World Health Organization. "WHO Guiding Principles on Human Cell, Tissue, and Human Organ Transplantation." 1991. Accessed 14 May 2016. <[http://www.who.int/transplantation/Guiding\\_PrinciplesTransplantation\\_WHA63.22en.pdf](http://www.who.int/transplantation/Guiding_PrinciplesTransplantation_WHA63.22en.pdf)>.

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