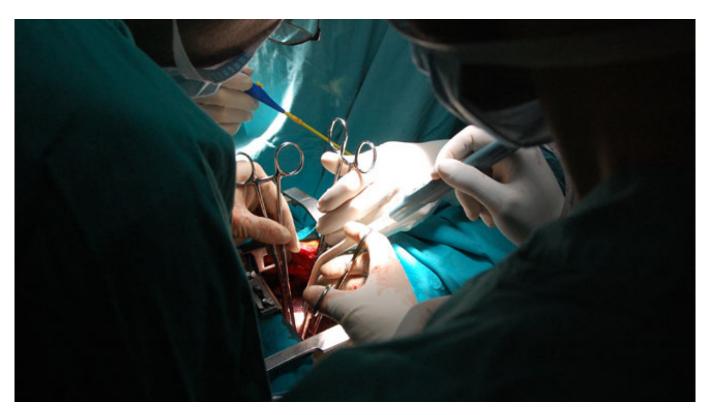


Russia's Unknown, Unwilling Organ Donors

By Anton Burkov

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After a road accident in January, Alina Sablina lay in a coma for six days. Her parents were with her in the hospital from the day after the accident until the day before her death. Only a month after the funeral did her parents find out that they buried their daughter without seven of her organs. While filling out paperwork in connection with the criminal case against the driver who caused the accident, her mother came across a forensic report that detailed the removal of her daughter's organs by Moscow City Clinical Hospital No. 1.

Another shock came with the news that only three — the heart and kidneys — of the seven removed organs were actually recorded in the list of removed organs. Four organs — part of her aorta and inferior vena cava, her adrenal gland, and a piece of the lower lobe of her right lung — were missing from the body and from the list of removed organs.

Alina never expressed her consent to donate her organs. Alina's parents were never informed about a planned organ transplantation and were not asked for their consent. This is despite their constant physical presence at the hospital and numerous discussions with the hospital's

doctors during six long days at the intensive therapy unit. Alina's parents were not allowed to see Alina on the last day of her life and were not given an explanation for this. Her parents believe she was being prepared for organ removal.

This was not an isolated incident. This is a structural issue — this is how the system works. The 1992 federal law on the transplantation of organs and/or tissues of human beings is a poorly written, three-page long text, full of gaps that create conditions for medical personnel to secretly harvest organs. In particular, Article 8 of this law establishes a presumption of consent on the part of an individual or close relatives to the postmortem removal of the deceased's organs for transplantation.

But the problem is not in presumed consent per se but in the lack of an obligation to actually inform parents of the planned transplantation. This unawareness subsequently turns into a violation of the human rights of the relatives. According to the European Convention on Human Rights, Russia guarantees that only relatives can make a decision regarding organ removal of their deceased family member. Alina's family did not make such decision. Alina's parents were ignored and are being ignored still.

Moreover, artificial presumed consent creates a lack of control over organ removal, leading to a lack of properly recorded transplant organs — which is all organized crime needs in order to sell unrecorded organs on the black market.

Finally, artificial presumed consent negatively impacts the attitude of the public toward organ transplantation. If doctors want the public to trust them, doctors must respect the decisions of family members when it comes to organ transplantation. If doctors act behind the backs of the public, the public will have no trust in them. Thus, artificial presumed consent must turn into informed consent or it will endanger the amount of willing organ donors.

Figures show that if transplantology is transparent, more people are willing to donate. The director of the Federal Research Center of Transplantology and Artificial Organs, Sergei Gautier explained that in 2010 there were 200 liver transplantations in Russia and 5,000 in the U.S. In the same year, 100 heart transplantations took place in Russia, while there were 2,500 in the U.S. If there were more organs available, there would have been more transplantations. Incidentally, the U.S. has a policy of expressed, not presumed, consent.

Over the two decades of the existence of artificial presumed consent and organ removal without the knowledge of family members, no doctors have ever been brought to justice for secret organ transplantation in Russia. This is partially due to the fact that only a small number of people know that organs of their deceased loved ones were removed.

The Russian Constitutional Court ruled on the constitutionality of presumed consent, concluding that it is "inhumane to put the question of harvesting organs or tissues to a person's relatives at practically the same time as they are notified of his death, or immediately before an operation or other type of medical treatment." Despite this, Alina Sablina's relatives have now applied for the European Court of Human Rights to consider their case, as they believe they have been subjected to inhumane and degrading treatment, a violation of the European Convention on Human Rights.

What could be done to remedy the problem of secret organ transplantation? A number of bills

on organ transplantation have been drafted already this year. None of these drafts deal with the most important issue: the legal status of relatives of the deceased who must be entitled to make decisions about the treatment of their family member. As things stand, their rights are ignored.

Presumed consent must cease to be artificial: The obligation of doctors to actively seek consent must be expressly stated in the law. The consent must be informed and only in exceptional circumstances of no immediate access to relatives can consent be presumed.

To avoid what the Constitutional Court called inhumane treatment, the consent must be received long before doctors use it to remove organs. The state must develop institutions that will facilitate obtainment of prior consent. This responsibility could be divided between a number of state authorities beginning with the Health Ministry, which should maintain a database of donors and run education campaigns about organ donation, similar to existing blood donation campaigns. The Interior Ministry should be responsible for including the desire to be an organ donor in passports and driver's licenses.

Hospitals must ensure that they have specially trained doctors on staff, responsible for approaching relatives of potential donors with questions about consent. The wealth of measures that are in place in other states is enormous and can be borrowed and adjusted to the Russian reality. This should be developed within a short time period but must not be rushed.

All Russian citizens should know that they are all presumed organ donors. This raises some worrying questions. Will artificial presumed consent guarantee medical treatment until the last hope is lost? Or will it merely guarantee a constant supply of unrecorded organs to meet a constant demand on the black market?

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