Third Section
European Court of Human Rights
Council of Europe
F-67075 Strasbourg CEDEX
France

#### BY E-TRANSMISSION ONLY

30 June 2017

## <u>Legal representative</u>:

Anton Burkov SROO Sutyajnik 620075, Russia, Yekaterinburg, Turgenev Str., 11-1 +79161250593 anton.burkov@qmail.com

Sablina and Others v. Russia No 4460/16

# Applicants' memorandum in reply to the Russian Government's memorandum

- 1. The applicants would like to submit their comments on the memorandum provided by Agent of the Russian Federation.
- 2. Facts. First of all, please accept some corrections of facts that shall be made in **STATEMENT OF FACTS.** 
  - 2.1. Page 1. "The third applicant lives in **Galdey**". The name "Galdey" shall be spelled as "Gadaley" (Гадалей).
  - 2.2. Page 1. "On 11 January 2014 Ms A.S. was hit by a car while crossing the street, sustained very serious injuries and fell into a coma." Ms Alina Sablina was crossing the street on zebra crossing. This fact has been established by a court. Although this fact has no influence on the outcome of the current case, it keeps a good memory of Ms Alina Sablina.
  - Page 2, paragraph 1. "On 17 January 2014 they arrived 2.3. again at the hospital, but were not allowed to see Ms A.S. because she had been moved to an intensive care ward." Ms Alina Sablina had been in the intensive care ward from the very first day at the hospital. Therefore, moving Ms Alina Sablina to the intensive care ward was not the reason for not allowing parents to see Ms Alina Sablina. Alina's parents, including the applicant Elena Sablina, were allowed to see Alina in intensive care ward on 13-16 January 2014. This was established by Zamoskvoretskiy district court of Moscow. However, on the 17 January 2014 they were refused access to Alina. The reason is unknown. Applicants claimed that Alina was being prepared for organ removal or already dead. We ask the ECHR to remove the following part from this

- contested sentence: "...because she had been moved to an intensive care ward."
- 2.4. Page 2, paragraph 2. "Despite the treatment she received Ms A.S.'s condition deteriorated and on 17 January 2014 at 11.40 p.m. brain death was recorded. According to official records, her relatives were notified immediately about her death. The applicants do not contest that they were informed but submit that they were not provided with details about the circumstances and cause of her death." Applicants indeed argue that Elena Sablina has not been notified about her death (See in Annex 16 to the Application No 4460/16 - "Civil Action (as amended 11.02.2015)"). It was one of the major points of the lawsuit. We ask this Court to mention that "The applicants contest that they were informed and that they were provided with details about the circumstances and cause of her death."
- 2.5. Page 2, paragraph 3. "On 18 January 2014 the heart and kidneys were removed from Ms A.S.'s body." At the trial applicants claimed and it was not contested by defendants and it was established by the courts that 6 organs were removed and only 2 (heart and kidneys) were recorded in the Act of organ removal. Four (4) organs went missing from medical record the Act of organs removal. We ask the Court to mention the following: "On 18 January 2014 six organs, including the heart and kidneys, were removed from Ms A.S.'s body. Four of the six organs were not recorded in the Act of organs removal."
- 2.6. Page 2, paragraph 5, sentence 2. "The forensic report stated, in particular, that a sterno-laparotomy had been performed on the body and that certain organs had been removed." The Forensic Report, No. 133/21, 11.02.2014 was clear on the list of organs removed and recorded. These were six organs removed in total and only two organs (heart and kidneys) recorded in the Act of organs removal, four organs (part of aorta, inferior vena cava, adrenal gland, and a piece of the lower lobe of the right lung) went missing from the Act of organs removal (Forensic Report, No. 133/21, 11.02.2014. Annex 4 to the Application No 4460/16). The applicants' would like to ask this Court to mention in the facts exactly what the forensic report stated.
- 2.7. Page 3, paragraph 3. "The applicants then brought civil proceedings against the Moscow City Health Department and the medical institutions involved in the organ removal before the Zamoskvoretskiy District Court of Moscow ("the District Court") seeking compensation of non-pecuniary damage". Applicants only sued hospitals.
- 2.8. Page 9, paragraph 2. "The applicants further submit that the participation of a public prosecutor in those

proceedings on the defendants' side breached the principle of equality of arms." Applicants claimed that participation of a state prosecutor in the dispute resolution between private parties in general, no matter on which side, is a violation, except in circumstances where a genuine state interest is at stake, which was not the case here. The mere fact of a state prosecutor present in private case is a violation of a fair trial. It is also very important to mention in the summary of facts that the prosecutor only read out her conclusion on the case without being present during the entirety of hearing which lasted all day on 6 April 2015 (see point 19, part E "Statement of the facts", Application No 4460/16).

- 2.9. Furthermore, the following complaint went missing in the "COMPLAINTS" part the complaint under Article 6 that applicants were denied to cross examine core witnesses of the case the transplantologists who removed Ms Alina Sablina's organs.
- 3. Comments on Government's memorandum.

## 4. General Comments.

- 5. After a road accident on 11 January 2014, Alina Sablina lay in a coma for six days. Her parents were with her at Moscow City Clinical Hospital No. 1 (the hospital) from the day after the accident until the day before her death on 17 January 2014. Only a month after the funeral did her parents find out that they buried their daughter without six 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 at the hospital.
- 6. Another shock came with the news that only two the heart and kidneys of the six organs removed were actually recorded in the list of organs removed. 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 organs removed.
- 7. Alina never expressed her consent to donate her organs<sup>1</sup>. Alina's parents have never been informed about planned organ transplantation and were not asked for consent of Alina or 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.
- 8. The Federal Act "On Transplantation of Human Organs and/or Tissues", dated 22 December 1992 (the 1992 law), is a poorly

<sup>1</sup> The system does not provide a mechanism for expressing such consent and documenting it. Today the only opportunity to establish consent is to ask close relatives when the worst is already happening or has happened. However, doctors ignore relatives and keep them uninformed regarding organ removal so that relatives could not express their decision regarding organs removal.

written, three-page text. Article 8 of the 1992 establishes an artificial (imputed) presumption of consent on the part of an individual or close relatives to organs removal of the deceased's post-mortem transplantation. The consent is artificial (imputed) because it is presumed even when close relatives are present at a hospital and resuscitators can approach and ask relatives for consent. Yet while doctors approach relatives to inform them of the condition of the patient, they do not inform relatives of organ removals already planned for transplantation and therefore do not ask for consent. At the same time same doctors inform transplantologists of the "potential donor" present at the intensive care ward. This is exactly what happened in the Case of Alina Sablina which was established by the Zamoskvoretskiy District Court of Moscow.

9. Article 8 provides that:

The removal of organs and (or) tissues from a corpse is not allowed if the health care institution at the time of removal <u>was</u> <u>informed</u> that this person during his life or his close relatives or legal representative stated their disagreement to removal of his organs and (or) tissues after death for transplantation to a recipient.

- 10. The key provision in this Article is that relatives must inform the medical institution about their attitude regarding removal of organs from a corpse. Instead of the medical institution, which plays a passive role, the close relatives of the patient must act and inform the medical institution of their objection to organ removal, as a rule, without any knowledge of pre-existing plans for organ removal, and therefore cannot freely make or express their decision.
- 11. The problem, therefore, is not presumed consent as such but lack of an obligation for doctors to actually inform close relatives about a planned organ removal. This unawareness subsequently turns into severe moral suffering for the relatives who end up discovering the truth. According to the Convention, ignorance of relatives' feelings (i.e. approaching them with information on deteriorating health conditions but failing to inform them of organ removal already planned) and ignorance of their decision-making power regarding organ removal violates the right to private and family life (Petrova v. Latvia)<sup>2</sup> and even amounts to inhuman and degrading treatment (Elberte v. Latvia)<sup>3</sup>.
- 12. In Alina's case, medical personnel had not informed her parents of the planned organ removal during any of their twice daily visits to the hospital over the six day period that Alina spent in intensive care. During this time the head

<sup>&</sup>lt;sup>2</sup> Petrova v. Latvia, 24 June 2014, No. 4605/05.

<sup>&</sup>lt;sup>3</sup> Elberte v. Latvia, 13 January 2015, No. 61243/08.

of the intensive care unit of the hospital did inform the Moscow Coordination Centre of Organ Donation about a "potential donor", Alina Sabina. According to the testimony of the head of the intensive care unit recorded in the Zamoskvoretskiy District Court's minutes, this occurred on the second day after Alina's arrival at the hospital, four days before her death (see Annex 25 to the Application No 4460/16). On all four days doctors spoke to Alina's parents about the declining health condition of their daughter. Therefore the parents did not and could not make any decision on organ donation and inform the hospital of their decision. Consent could not be presumed in such a situation. The ability of doctors to approach the parents, but failure to do so, makes presumed consent artificial (imputed) and leads to a violation of the parents' rights under the Convention.

- 13. The system does not provide a mechanism for expressing such consent in advance or at the moment of death and for documenting it. Today the only opportunity to establish consent is to ask close relatives when the worst is already happening or has happened. However, doctors can somehow ignore relatives and keep them uninformed regarding organ removal.
- 14. The applicants want to stress that secret organ harvesting is practiced systematically in Russia. Every case of organ removal is simply carried out without the consent of a donor or their relative(s). The reason for small number of such cases known to the public or reached the courts is that organ removal is carried out in secret. Therefore relatives are unaware of the fact that organs were removed. Therefore they buried their loved ones without some organs not knowing the latter.
- 15. **Preliminary consent.** The fact that there is no system of asking for consent during the lifetime of a donor is not contested by the Government. The absence of such a system in Russia is seen from the analysis of the 1992 law.
- 16. Post mortem consent.
- 17. Russian doctors openly confirm that they do not inform close relatives of the planned organs removal. Testimonies given by doctors involved in the process of organ removal confirm that ignoring the wishes of close relatives is not an isolated incident but rather part of a general practice following the 1992 law on transplantation<sup>5</sup>.

<sup>&</sup>lt;sup>4</sup> The only medical institution authorized to carry out organ removal for further transplantation. Second defendant in the Sablina case.

<sup>&</sup>lt;sup>5</sup> Olga Karaeva, *Donorstvo organov: problemy i perspektivy razvitiya v Rossii* (Moskva: Levada-Tsenter, 2013), 40-42 (Olga Karaeva, Organ Donation: Problems and Prospects Development in Russia (Moscow: Levada-Centre 2013), p. 40-42). Available at

http://www.levada.ru/old/sites/default/files/otchet\_donorstvo\_organov\_v\_rossii\_l
evada-centr.pdf.

- 18. On a number of occasions doctors confirmed that they are not obliged to ask for consent from relatives or inform them about planned organ removal. Igor Loginov, intensivist (анестезиолог-реаниматолог) of the Saint-Petersburg Center of Organ and Tissue Donation (Центра органного и тканевого донорства Санкт-Петербурга) on the 23:20 minute of the documentary "Transplantology. Challenge to the Death." ("Трансплантология. Вызов смерти.") said that: "We actively are not obliged to ask for consent of relatives" ("Мы активно спрашивать согласия родственников не обязаны").6
- 19. Admissibility.
- 20. Government's position. The Government mentioned that on 10 July 2014 the applicants has already applied to the ECHR (Application no. 52859/14) and this application was ruled inadmissible.
  - Applicants' position. Application no 52859/14 was filed 20.1. on the same facts but before exhausting domestic remedies. In this application we argued that there were no effective remedies available, therefore it was filed before exhaustion of domestic remedies. Apparently not accepting the applicants' argument on lack of effective domestic remedies (decision on inadmissibility is not clear about specific reasons), this Court ruled the application no 52859/14 inadmissible on 29 January 2015. During (not after decision of inadmissibility as Government mentioned in the memorandum) consideration of Application no 52859/14 by this Court, applicants went to national courts to exhaust domestic remedies be they as ineffective as they proved to be. This was done particularly due to the representative of the applicants envisaged the inadmissibility of the application no 52859/14 and also because the need of discovery of facts through litigation. After going through all the Russian courts applicants applied to the ECHR within the 6-month time limit. And this second application No 4460/16 is now before the ECHR.
  - 20.2. All these facts were provided to the ECHR by the applicants in the Application No 4460/16 see point 44 on page 13 of the Application No 4460/16 and Annex 44 "ECHR's letter of 29.01.2015" to the Application No 4460/16.
- 21. Government's position. Government said that application to national courts with civil case is not an exhaustion of domestic remedies as the time limit for civil cases is not

6

<sup>&</sup>lt;sup>6</sup> 23 Minute 20 second of the documentary "Transplantology. Challenge to the Death." ("Трансплантология. Вызов смерти."). Available at <a href="http://russia.tv/brand/show/brand\_id/58423">http://russia.tv/brand/show/brand\_id/58423</a>.

- set, it can be brought at any point in time and that it will not lead to criminal investigation just to compensation.
- 21.1. Applicants' position. The reason of the sufferings of the applicants is in the 1992 law and its application by medical staff and law enforcement organs, including the courts, particularly the Russian Constitutional Court. Deriving from this, the goal of the applicants is to challenge the legislation and the way it is implemented so that no secret organ harvesting ever takes place again. Civil lawsuit leading to the complaint before the Constitutional Court was the only presumably effective domestic remedy available to the applicants which they pursued accordingly and in due course.

#### QUESTION 1

- 22. Government's position. The Government argues that there was no violation of Article 8. The Government argues that relatives have the burden of informing the hospital of any objections regarding organ removal, rather than putting on hospitals burden to inform parents of planned organs removal, and seek consent.
  - 22.1. Applicant's' position. If we look at Article 8 of the 1992 law through the lenses of Article 8 of the Convention as it is interpreted in Petrova v. Latvia and Elberte v. Latvia, we see that 1992 law contradicts to the principle of clarity of the law. Paragraph 96 of Petrova v. Latvia states:

"While Latvian law set out the legal framework allowing the closest relatives to express their wishes in relation to organ removal for transplantation purposes, it did not define with sufficient clarity the scope of the corresponding obligation or the discretion conferred on medical practitioners or other authorities in this respect."

- 22.2. The situation in this case is identical. The rule of Article 8 of the 1992 law is not clear enough for the close relatives to follow. Under Article 8 of the 1992 law relatives are obliged to inform of objection to organs removal without any knowledge of the planned removal of organs. This rule of the 1992 law is not clear because it contains a trap for relatives in general and applicants to this case in particular. The applicant Elena Sablina did not show any objection to organs removal from Alina Sablina because she had no information from the hospital regarding organs removal of her daughter Alina, planned by the hospital and transplantologists for at least 4-5 days. She had no information (no access to information) about the subject of possible objection.
- 22.3. In the present case, it remains unclear how the "presumed consent system", as established under the Russian law, operates in practice in the circumstances in which the applicants found themselves, whereby they

had certain rights as the closest relatives but were not informed - let alone provided with any explanation - as to how and when these rights might have to be exercised.

- 23. Government's position. The Government says that relatives have to prove that they expressed objection.
  - 23.1. The Government omits the general rule that no one can express an objection to what is unknown. The applicant Elena Sablina says that she was not informed of the planned organ removal, therefore she could not express her attitude regarding unknown fact.
- 24. The Government considers that publication of the law on transplantation of organs is enough for relatives to express their attitude towards organs removal.
  - 24.1. This means that the only way of knowing the fact of planned organ removal is to guess that organs will be removed according to the 1992 law. Therefore the Government's argues that publication of the 1992 law is enough, that there is no need to inform close relatives of the potential donor of planned organ removal is a legal trap. This is how the Government understand presumptive consent. In practise application of Article 8 of the 1992 law makes consent imputed (BMeHeHHOe) consent, not presumed.
- 25. Government's position (Points 23-24). Some changes to the 1992 law were made after 4 December 2003 (first decision of the Russian Constitutional Court in which it ruled for "secret" organ removal, suggesting minor changes to the 1992 law). The Government said that under the changes to the 1992 law relatives' consent could be expressed in the same way as donor's.
  - 25.1. Applicant's' position. The changes have not made any difference and have not prevented secret organ removal from Alina Sablina. There is no procedure in place according to which donors (those under Russian jurisdiction) or their relatives could express their consent. Such mechanism simply does not exist. The Government did not prove that it exists. The Government provided no data (a number of consents recorded) which demonstrates that the mechanism is in place and works.
- 26. Government's position (points 27-28). Russian system corresponds to international practice of presumed consent.
  - 26.1. Applicant's' position. None of the existing systems of presumed consent in the world allows situations where consent is not sought at all. Only Russia has a system where no consent is sought during the lifetime of donors, where no consent is asked from close relatives of the donor after his or her death. For example, in Spain, the most successful State with a presumed consent system, presumed consent means asking consent when possible, for example, when parents of the potential donor are available to provide consent for a period of

maximum 5 days during which the donor is at the intensive care ward. In Latvia, the presumed consent system has been changed in the aftermath of Petrova v. Latvia and Elberte v. Latvia cases. The system in Latvia now function in a similar fashion as the spanish model. In Russia, presumed consent means not asking for consent at all, even in the situations when parents are available to talk to during 5 days. So it is not presumed but "imputed" (BMeHeHHOe) consent.

- 27. Government's position (point 30) "applicants admitted that Alina Sablina did not express disagreement on the question on possible removal of her organs in case of death", "applicants did not provide any evidence that they objected to removal".
  - 27.1. Applicants' position. This case is not only about whether wishes of Alina Sablina were followed. This case is about sufferings of the applicants due to the fact that doctors in the intensive care ward failed to inform Alina's parents of planned organs removal, failed to ask Alina's parents if Alina has ever expressed her consent to organ donation or if Alina's parents consent to Alina's organ donation. This case is about the 1992 law allowing doctors to remove organs in secret from close relatives (parents) of the donor and sufferings which is caused by this law.
- 28. Government's position (point 32). The 1992 law on transplantology of organs was published and mass media informed many about the 1992 law.
  - 28.1. Applicants' position. The 1992 was published long before Alina Sablina's birth. This fact objectively prevented her from reading this law.
  - 28.2. Applicants point out to two social surveys on this matter both observed little knowledge of the population.
  - 28.3. First report was run online by NGO Sutyajnik ОТЧЕТ о результатах социологического исследования «Трансплантация (пересадка) органов умерших пациентов без их прижизненного согласия или согласия их близких родственников» (Report on the results of sociological research "Transplantation (removal) of organs from deceased patients without their consent in their lifetime, or the consent of their relatives"). (Report is attached see Annex 1 to this memorandum). The vast majority of population (62.3 per cent) did not know anything about the fact that doctors may remove

-

<sup>&</sup>lt;sup>7</sup> Report on the results of sociological survey "Transplantation (removal) of organs from deceased patients without their consent in their lifetime, or the consent of their relatives", Yekaterinburg, NGO Sutyajnik, 2017, is also available online <a href="http://sutyajnik.ru/documents/5030.pdf">http://sutyajnik.ru/documents/5030.pdf</a> (Annex 1)

- their organs without their consent in his/her lifetime consent (page 32 of the NGO Sutyajnik's report).
- 28.4. The second sociological report led to the following conclusion: "The analysis of the data showed that organ donation and organ transplantation are subjects which are quite complex and unfamiliar to respondents." (see Page 45 of the Report, Annex 2)8.
- 29. Government's position (point 37). Draft law on organ donation was introduced by the Russian Ministry of Health to the Russian Government for approval.
  - Applicants' position. On 12 April 2017 Gabbasova Lialia 29.1. Adygamovna, assistant to the Russian Minister of Health (Габбасова Ляля Адыгамовна, помощник министра Здравоохранения России), speaking at conference "Implementation of International and Constitutional Guarantees of Human Rights in Russian Law and Practice" ("Реализация международных и конституционных гарантий прав человека в российском праве и правоприменительной практике") with the talk "Questions of bioethics in medical practice in Russia (surrogacy, transplantation)" ("Вопросы биоэтики в медицинской практике в России (суррогатное материнство, трансплантология)") confirmed that the notion of "presumed consent" in the draft law is unchanged. 10 Article 18 of the draft law on Transplantation of Organs is unchanged - paraphrased but similar to Article 8 of the 1992 law (Annex 3).
- 30. Government's position (point 40) people's opinion was taken into account.
  - 30.1. The applicants' opinion, including their representative, was not taken into account. No representative of the Ministry of Health contacted the applicants for their opinion regarding the new draft law, particularly its presumed consent. All the attempts of the applicants' representative to get in touch with the Ministry of Health regarding the draft law were in vain. The most recent attempt took place on 12 April 2017 at the MGIMO and the Council of Europe conference when the applicants' representative spoke to Gabbasova Lialia Adygamovna.

<sup>&</sup>lt;sup>8</sup> Olga Karaeva, *Donorstvo organov: problemy i perspektivy razvitiya v Rossii* (Moskva: Levada-Tsenter, 2013), (Olga Karaeva, Organ Donation: Problems and Prospects Development in Russia (Moscow: Levada-Centre 2013). Available at <a href="http://www.levada.ru/old/sites/default/files/otchet\_donorstvo\_organov\_v\_rossii\_levada-centr.pdf">http://www.levada.ru/old/sites/default/files/otchet\_donorstvo\_organov\_v\_rossii\_levada-centr.pdf</a> (Annex 2).

 $<sup>^{9}</sup>$  This conference was organized by MGIMO university in cooperation with the Council of Europe.

<sup>&</sup>lt;sup>10</sup> The recording of her talk is available at <a href="http://sutvajnik.ru/news/2017/04/2775.html">http://sutvajnik.ru/news/2017/04/2775.html</a>

- 31. Government's position (point 41-48). Russia is a country with the smallest number of transplantations.
  - 31.1. Applicants' position. The sociological survey by Levada confirms that the reason for small number of donors is not due to not enough people giving consent needed for removal of organs. As we learned above under the 1992 law no doctor needs a consent to continue with organ removal, no doctor is obliged to inform of planned organs removal. Under the 1992 law all doctors need is to keep their mouth shut about planned organ removal. Therefore the real reason for insufficient number of donors is in lack of interest of reanimatologists to work with transplantoligists:

"The mechanisms of the expression of the will have not been established. As a result, the law is sufficiently broad framework for organs removal after the death of patients. However, the figures for the number of donors in Russia remain 3-4 times lower even in comparison with countries where the system of organ donation is based on more stringent criteria for obtaining permission to use the organs (Spain)." (page 6 of the Report, Annex 2) ("Сами механизмы выражения не были. В результате, волеизъявления созданы предоставляет достаточно широкие рамки для забора органов после смерти пациентов, однако, показатели по количеству доноров в России остаются ниже в 3-4 раза даже по сравнению со странами, где система донорства основана на более жестких критериях получения разрешения на использование органов (Испания)." (стр. 6 соцопроса, Annex 2).

31.2. Levada addressed its own question "Why the real indicator of organ donation remains low when formally enshrined principle of apriori consent for the formation of the list of postmortem donors?" ("В связи с чем при формально закрепленном принципе априорного согласия на становление посмертными донорами, показатель реального донорства остается таким низким?"):

"The call for a team of coordinators or transplantologists is administrative obligation based on doctors-resuscitator. A message about a potential donor to the coordination or transplantation center means immediate start of the whole mechanism of the organization of work with donor - resuscitation procedures to support the work of donor's organs, conduct monitorings of donor's condition. In this respect the institutional gap between formal norms and informal rules of behavior of medical personnel occurs. There is no such obligation in law - one can call [a team of coordinators or transplantologists], but at the same time one can refrain from calling the experts. As a result, the bond between hospitals and transplant centers is broken." (page 38 of the Levada report, Annex 2) ("Вызов бригады координаторов трансплантологов не имеет под собой административной обязанности для врача-реаниматолога. Сообщение о появлении потенциального донора в координационный или трансплантационный центр означает незамедлительный запуск всего механизма по организации работы с донором - проведение реанимационных процедур для поддержания работы органов донора, проведение обследований и мониторинг его состояния. В этом отношении происходит институциональный разрыв между формальными нормами и неформальными правилами поведения медицинского персонала — законодательно такой обязанности нет — можно вызвать, а можно не вызывать специалистов. В результате, связка между лечебными учреждениями — центрами трансплантации оказывается нарушена." (стр. 38 соцопроса, Annex 2)).

31.3. This is how lack of interest for cooperation is expressed by doctors-resuscitator:

"If we treat patients badly or if we have not cured a patient [...] we can be blamed. That is, we are responsible. But if we lost a donor, there is no accountability. For no one is punished. And the lack of this responsibility, in fact, is a motive not to do this work" (head of Department of coordination, Moscow). "Если мы плохо лечим или вылечили, с той или иной патологией, там, с аппендицитом, с инфарктом человека, нас могут ругать. То есть, мы несем ответственность. А вот если мы потеряли донора, то за ответственности не существует. За это никого не накажут. И отсутствие этой ответственности, собственно говоря, это мотив для того чтобы не делать работу" (заведующий отделением координации, Москва).

The Levada report continues: "The other side of this process is that the structure of motivational incentives to doctors of medical institutions is not in place. Implementation of all additional loads to work with potential donor occurs without any remuneration or the physical and compensation for time (Другая сторона этого процесса СОСТОИТ что структура В том, мотивирующих стимулов для врачей лечебных учреждений также выстроена. Осуществление всей дополнительной нагрузки по работе с потенциальным донором происходит каких-либо вознаграждений компенсаций физических и временных затрат:):

"We do not receive any remuneration for this work. This is our good deed. Somewhere in the West, you know, any work is paid. I understand how important this is. Most do." (Head of Department of intensive care unit, Saint-Petersburg). (" $M \, \text{bl}$ 

за это вообще ничего не получаем. Это наше доброе дело. Где-нибудь на западе, понимаете, любая работа оплачиваема. Это дело идет к тому, что я понимаю, как это важно. Собственно, все у нас заведующие отделения реанимации больше вообще-то понимают, как это важно" (зав.отделением реанимации, Санкт-Петербург)).

"And here is the chief doctor, where this donor is placed, says: "Why do I need this? The person is already dead. I do not have the right to write off medicine and the time doctors spent on a patient, and so on and so forth. It is easier for me if there is no donor" (transplantologist of kidneys, Moscow) (p. 38-39 of the Levada report, Annex 2). («И вот тот главный врач, где находится вот этот донор, он говорит: "А зачем мне это надо? Человек уже мертв. Я на него не имею права списывать лекарства, затрату времени врачей и так далее и так далее. То есть мне проще, чтоб его не было"» (трансплантолог почки, Москва) (стр. 38-39 соцопроса, Annex 2)).

- 32. Government's position (point 49). "Intervention in the rights of the applicants was carried out according to the statute, persuaded legitimate aim and was necessary."
  - statute is 32.1. Applicants' position. The vaque. vaqueness allows doctors to altogether conceal removal information planned organ on from close relatives of the patient ("potential donor").
  - 32.2. In this case of Alina Sablina there was no legitimate aim in removal of her organs as four (4) organs went missing, they were removed from Alina not for the purpose of transplantation. The Government failed to mention the whereabouts of those organs.
  - 32.3. It was not necessary to make applicants suffer because of the secrecy of the procedure. The organ removal procedure could be open without unduly interfering with the transplants. Instead, the Government decided to keep the system secret as it exists today, namely a system in which public agents have unfettered discretion when it comes to seeking close relatives' consent prior to organ transplants. Such a system is incompatible with the right to private life guaranteed under Article 8 of the Convention, as is demonstrated by the harm suffered by the applicants in the present case.
  - 32.4. The Government failed to address grandmothers separately despite the invitation from the ECHR to do so.

- 33. Government's position (point 60). The applicants have not been subjected to inhuman and/or degrading treatment. (point 63) sufferings were connected with the death, and other circumstances but not the removal or organs.
  - 33.1. Applicants' position. In reply the representative of the applicants would like to highlight the interview of Elena Sablina to various media outlets which could be summarized as saying that "When I learned that Alina's organs were removed I felt that I lost my daughter for the second time" and other quotes from the written motion dated 6 April 2015 to enclose evidence (the list of exhibits) of moral sufferings by Elena Sablina to the Zamoskvoretskiy district court case file (see Annex 24 to the Application no 4460/16).
- 34. Government's position (point 65): "Removal of Alina's organs was not reflected on the exterior of the body of Alina."
  - 34.1. Applicants' position. Applicants chose not to reply or comment to this point as the latter is a deviation from the question this Court asked. The applicants have never claimed non-pecuniary damages due to "Removal of Alina's organs reflected on the exterior of the body of Alina." The applicants suffered due to secret organ removal.
- 35. Government's position (point 67) circumstances of Sablina case is different from Elberte v. Latvia.
  - 35.1. Applicants' position. Applicants and their representative do not see practical difference between mentioned cases. In fact, similarities between the cases were explained in every application, motion, or oral arguments submitted to all the national courts.
- 36. Government's position (point 68) there was an autopsy but applicants agreed with it and this is a normal procedure.
  - 36.1. Applicants' position. Applicants chose not to reply or comment to this point as the latter is a deviation from the question this Court asked. The Government deviates the attention of this Court from the issue secret removal of organs and not knowing whereabouts of 4 organs out of 6 removed (2/3 of removed organs). No mention as to the whereabouts of the 4 missing organs from the body of Alina, which is unacceptable.
- 37. Government's position (point 69): "missing [they mean the two recorded organs] organs hardly could influence emotional state of applicants more than the fact of death of Alina".
  - 37.1. Applicants' position. Representative of the applicants would like to repeat that Elena Sablina's feelings about secret organ removal from her daughter's body: "When I learned that Alina's organs were removed I felt that I lost my daughter for the second time" (see Annex 24 to the Application no 4460/16).
- 38. Government's position (point 70): in the case of Petrova v. Latvia the ECHR concluded that it was not necessary to

consider application under art 3 because it was connected with art 8 which has been already addressed.

38.1. Applicants' position. In Petrova v. Latvia, the Court decided that it was not necessary to decide whether there had been a violation of Article 3 because of its finding under Article 8. The Court decided to exercise its discretion because of the two alleged violation under Articles 3 and 8 were closely related. Conversely, in Elberte v. Latvia, the Court found violations under both articles. The Court explained, that "in order for a separate violation of Article 3 to be found in respect the victim's relatives, there should be special factors in place giving their suffering a dimension and character distinct from the emotional inevitably stemming from the aforementioned violation itself" (para. 137). In Elberte, the closeness of the family bond and the way the authorities responded to the relative's enquiries were said to be relevant factual elements capable of bringing the relatives' sufferings within the scope of Article 3. The Applicants submit to the Court that both special factors are present in this case. Firstly, it is undisputed that a close family bond existed between Alina and the Applicants. And that family bond combined with illegal (in violation of the Convention) actions of the authorities cause applicants non-pecuniary sufferings (See Annex 24 to application No 4460/16). Secondly, medical authorities completely ignored interests of the Applicants knowing what is being done to the body of Alina and ignored their wishes. The law enforcements authorities dismissed the Applicants' claim to fully understand what happened with Alina's organs. The State has vigorously contested the legal proceedings initiated by Applicants before seven (7) Russian domestic courts (Zamoskvoretskiy District Court, the court of appeal -Moscow City Court, the court of cassation - the Presidium of Moscow City Court, the court of cassation the Supreme Court of Russia, the Constitutional Court applicants initiated three the cases before the Constitutional Court). All these litigations initiated to fully investigate why the applicants' feelings and wishes were ignored, what have been done to Alina's body. Instead of effectively dealing with the applicants' cases, authorities threatened Elena Sablina with criminal proceedings (see Annex 15 to the Application No 4460/16).

#### QUESTION 3

39. Government's position. The trial hearings were closed for public because it was necessary to protect medical information of Alina.

- Applicants' position. The applicants were not arguing that Alina was treated in the hospital in a wrong way. The lawsuit did not rest on any such argument. The only applicants advanced was that arqument organs removed secretly. To demonstrate this argument, there is no need to divulge secret medical information or secrecy regarding Alina's treatment. Information about organ in the public domain. removal was already This initiative was advanced by defenders for the only purpose of seeking a closed hearing away from the public eye under false pretences. The defendants could have asked the court to close the hearing for certain number of minutes to discuss the medical treatment and open the hearing for the rest of the proceedings. defendants asked the court to close the entire hearing with the only goal of concealing the entirety of the facts of the case from the attention of the public and the media. This is especially true with regards to the appeal hearing because according to the minutes of the appeal hearing (Annex 35 of the Application No 4460/16) no medical information was discussed at all. This point of the applicants was raised before every court and was fully ignored by all the courts.
- 40. Government's position (point 88): The applicant's representative of applicants participated in cross examination of witnesses.
  - 40.1. The applicants' position. The court refused the applicants' representative to examine main witnesses, namely the transplantologists (see point 18 of the Statement of facts on page 10 in the Application No 4460/16 and Annex 23; also see point 5 of "F. Statement of alleged violation(s) of the Convention" of the Application No 4460/16).
- 41. Government's position (point 89)
  - 41.1. The applicants' position. Applicants received a copy of the judgment which was never publicly announced or published in paper or online. On the web-site of the Moscow city court this judgment is classified as not for public (see Annex 4).
- 42. Government's position (point 92): the state admitted that the prosecutor was not required in the hearing.
  - 42.1. The applicants' position the procurator participated in the form of presenting to the court the procurator's position with conclusions on the matter of the case. The latter could influence the judge and in fact her only aim was to influence the judge. The procurator was not present at the hearing at the stage of examination of evidence. Procurator only appeared at the conclusive part of the hearing parties' closing arguments to read our procurator's conclusion. This means that the procurator made her conclusions without knowledge of the

- case and any evidence which was presented. These circumstances confirm that the procurator's reading out the conclusion had the only goal to influence the judge rather than examine all facts of the case which she clearly did not do.
- 42.2. On 12 January 2017 the legal norm of the Civil Procedure Code which allows this behaviour of the prosecutor was challenged before the Constitutional Court of Russia (Annex 5). Applicant Elena Sablina is still awaiting for a decision of the Russian Constitutional Court. Full update on the litigation which led to the application to the Constitutional Court was submitted to the ECHR in the letter dated 28 April 2016 which reached the ECHR on 6 May 2016.
- 43. Applicants would like to update this Court on the outcome of the applicants' complaint considered by the Russian Constitutional Court on the issue of constitutionality of the "presumed consent" of Article 8 of the 1992 law as it is interpreted in the medial and court practice. This applicants' initiative was mentioned in point 40 on page 13 of the Application No 4460/16. The complaint to the Constitutional Court and follow up communication with the Constitutional Court was attached to the Application No 4460/16 (see Annexes 41-43). The Constitutional Court issued Decision No 224-0 of 10 February 2016 on inadmissibility of the complaints. The ECHR was updated about this by letter of 3 June 2016 received by the ECHR on 14 June 2016. The complaint to the Constitutional Court and Decision No 224-0 of 10 February 2016 was annexed to the letter dated 3 June 2016.
- 44. The applicants' to this case also challenged before the Constitutional Court provisions of the Civil Procedure Code which allows the court to close the hearing from the public during the entirety of the hearing and not publish the final judgment. The complaint to the Constitutional Court dated 23 November 2016 and the Decision by the Constitutional Court No 1063-O of 25 May 2017 is annexed to this memorandum for information of this Court (Annex 6-7 to this memorandum).
- 45. CLAIMS FOR JUST SATISFACTION. COSTS AND EXPENSES
- 46. Claims for Just Satisfaction. The applicants claim 24000 € each for compensation of their non-pecuniary damage. This claim is based on the ECHR case-law Petrova v. Latvia and Elberte v. Latvia. Applicants claim that there was inhuman and degrading treatment (violation of Article 3) in addition to violation of private and family life (Article 8). Due to the similarities of facts of Sablina and Others v. Russia with the circumstances in Petrova and Elberte, the applicants claim 16000 minimum for violation of Article 3 and 8. Taking into account that the way to the ECHR the applicants had to fight through violations of their right to fair trial (no possibility to cross examine main witnesses, participation of

the prosecutor, lack of public access to the hearing and to the case-files, including judgments) without access to an effective remedy, including the Constitutional Court (Article 13), the applicants claim additional 8000 EUR as a compensation for non-pecuniary damage caused by violation of Article 6 and 13. In total each applicant claim 24000  $\in$  for compensation of their non-pecuniary damage. Grand total is 24000  $\in$  X 3 = 72000  $\in$ .

- 47. **Costs.** The applicants claim compensation of legal costs of 2 812 500 \( \text{M}\) (37 500 \( \ext{E}\)) which they incurred in order to obtain redress for the alleged violation of the Convention, both within the domestic legal system and through the ECHR proceedings since 2014. Legal costs are substantiated in the agreement on legal services and act of carrying out legal services (Annex 8-9).
- 48. Expenses (Annex 10):

postal costs					
1	02.07.2014	courier service expenses for delivering documents from Elena Sablina to Anton Burkov in Washington D.C. to the ECHR	\$ 144.28		
2	10.07.2014	postal expenses - first application to the ECHR	\$ 43.05		
3	27.07.2015	postal expenses - letter to the Constitutional Court	141,97		
4	5.10.2015	postal expenses - letter to the Constitutional Court	74		
5	13.10.2015	postal expenses - letter to the Qualification collegium of judges	42		
6	11.12.2015	postal expenses - letter to the Constitutional Court	44		
7	25.12.2015	courier service expenses - application to the ECHR	2286.00		
8	12.01.2016	postal expenses - letter to the ECHR	194.00		
9	28.04.2016	postal expenses - letter to the ECHR	265.00		
10	12.05.2016	postal expenses - letter to the ECHR	187.50		

	1		1
11	01.06.2016	postal stamps	35
12	14.12.2016	cost of notarizing power of attorney	1200
courts	fee		
13	27.10.2014	fee for application to Zamoskvoretskiy district court of Moscow	200
14	20.04.2015	fee for submitting appeal to Moscow City Court	150
15	20.07.2015	fee for application to the Constitutional Court challenging Article 8 of the 1992 law	450
16	31.08.2015	fee for application to the Supreme Court	300
17	10.01.2017	fee for application to the Constitutional Court challenging the law allowing participation of the prosecutor	450
travel	costs		
18	13.09.2014	ticket Moscow-Ekaterinburg from the submission of the initial lawsuit on behalf of Sablina	11077
19	29.09.2014	ticket Ekaterinburg-Moscow for the submission of additional document to the lawsuit	7267
20	14.11.2014	ticket Ekaterinburg-Moscow for investigating matters and meetings with defendants	1000
21	22.11.2014	additional fee for ticket of 27.11.2015 Ekaterinburg-Moscow	6400
22	27.11.2014	ticket Ekaterinburg-Moscow for investigating matters and meetings with defendants	9590

23	07.12.2014	ticket Ekaterinburg-Moscow for investigating matters and meetings with defendants	8519.50
24	8.12.2014	hotel ZAO TGK "BETA" 8.12.2014-12.12.2014	24000
25	18.12.2014	ticket Ekaterinburg-Moscow for investigating matters and meetings with defendants	7330.20
26	30.12.2014	train ticket Moscow-Serov from the hearing on 23.12.2014	13760.80
27	07.01.2015	train ticket Serov-Moscow for the hearing on 29.01.2015	13367.90
28	4.03.2015	ticket Moscow-Yekaterinburg from the hearing on 2.03.2015	6830
29	6.03.2015	ticket Yekaterinburg-Moscow for investigating matters	6870
30	11.04.2015	ticket Moscow-Yekaterinburg from the hearing on 6-7.04.2015	6835
31	19.04.2015	ticket Yekaterinburg-Moscow for the submission of appeal on the judgment of 7.04.2015	3624
32	22.07.2015	ticket Yekaterinburg - Moscow for 28.07.2015 hearing on entering correction to minutes of the hearings of 6-7.04.2015	14396
33	26.09.2015	train ticket Yekaterinburg-Moscow for investigating whereabouts of the cassation and receiving copies of judgments	8160
34	30.09.2015	ticket Moscow-Yekaterinburg-Moscow for investigating whereabouts of the cassation	8578

35	22.11.2015	train ticket Moscow-Ekaterinburg	5275.50
36	26.11.2015	ticket Yekaterinburg-Moscow for collecting judgments for submission of the application to the ECHR	7250
other o	costs		
37	15.02.2015	printing paper	780
38	13.03.2015	printer cartridge refill	700
39	17.03.2015	printer cartridge repair and refill	2500
40	01.09.2016	stationary	2490
41	3.09.2016	copy service for submitting complaint to the Constitutional Court	1899
42	11.09.2016	copy service for submitting complaint to the Constitutional Court	498
		TOTAL IN 🛭	125 252.97 🛚
		TOTAL IN \$	187.33 \$

- 49. In total the applicants claim
  - 49.1. **24** 000 € each for compensation of their non-pecuniary damage. Grand total is 24000 € X 3 applicants = **72000** €.
  - 49.2. **2 812 500** ☑ for compensation of legal costs to be payed to their representative directly who bore the costs.
  - 49.3. 125 252.7  $\boxtimes$  and 187.33  $\ddagger$  for compensation of expenses.

## Annexes (enclosures):

- 1. Report on the results of sociological survey "Transplantation (removal) of organs from deceased patients without their consent in their lifetime, or the consent of their relatives", Yekaterinburg, NGO Sutyajnik, 2017.
- 2. Olga Karaeva, Donorstvo organov: problemy i perspektivy razvitiya v Rossii (Moskva: Levada-Tsenter, 2013), (Olga Karaeva, Organ Donation: Problems and Prospects Development in Russia (Moscow: Levada-Centre 2013
- 3. Draft law on Transplantation of Organs.
- 4. Screenshot of the web-page of the Moscow city court's web-site.
- 5. The 12 January 2017 application of Elena Sablina and Yuriy Mironov to the Constitutional Court of Russia.

- 6. The complaint to the Constitutional Court dated 23 November 2016.
- 7. The Decision by the Constitutional Court No 1063-0 of 25 May 2017.
- 8. Agreement dated 5 April 2014.
- 9. Act of carrying out under the agreement dated 5 April 2014.
- 10. Receipts of expenses (42 pages).

Yours faithfully,

Anton Burkov
The applicants' legal representative

22