



Legislative proposal in Italy to facilitate contacts between deceased organ donor families and transplant recipients

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Abstract

Contacts between organ donors and recipients might be possible in the near future in Italy. As suggested by The Italian Committee of Bioethics “anonymity is requested by the Italian National Transplant Centre” before transplantation anonymity shall be strict in order to grant privacy, gratuity, justice, solidarity and benefits and avoids organ trafficking. Following a period that is ethically correct and justifiable, organ donor families and recipients can meet after signing a valid declaration of consent, expressed on a template valid for the whole country. A third party within the body of the National Health Systems shall control the validity of the consent. The opinion stresses that contacts are not a right but a possibility justifiable on ethical grounds if the procedure is followed appropriately. A legislative proposal has been presented before the Chamber of deputies incorporating all suggestions made by the National Committee of Bioethics. The agreement between parties might be signed a year after transplantation. This is a long enough period of time for the recipients to fully appreciate the benefits of the procedure and for the donor families to see the effects of their decision (the opinion and the Law proposal hit the Zeitgeist, and keep Italy in the regulation of European Union).

Keywords Anonymity · Organ donation · Donor families · Recipients

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Introduction

Organ transplantation is a life-saving procedure. It is the gold standard for end-stage renal disease since it offers the highest quality of life and the longest survival at the lowest cost for society. The major limitation to renal transplantation nowadays is the paucity of living and deceased kidney donors. It is commonly believed that better public awareness could improve the number of organ donations. It has also been suggested that meeting the transplant recipient could help the donor families to mourn. On this particular issue in the organ donation process there is no consent. World Health Organization (WHO) recommends anonymity, whereas in the USA contacts between donor families and organ recipients are possible if both parties agree. There is an ongoing International debate between supporters of anonymity and those requesting that donor families should be allowed to meet the transplant recipients. While the issue is controversial there are reasons to support and to break anonymity in organ donation.

Why anonymity?

Anonymity grants respect of the individual's right to privacy of information that is considered a key element in today's medical care of donor families and recipients. There are donor families unwilling to establish contacts with the transplant recipient to escape re-experiencing the organ donation process. Also on the recipient's side, meeting the donor family could be a very stressful situation, remembering that he/she is enjoying a new life because someone else has died. Most of the time donor families are willing to meet the transplant recipient, while a minority of patients are in favor of rescinding anonymity. Even in the United States where meetings between donor families and transplant recipients are possible when both sides agree, the number of contacts is scanty. After transplantation recipients are generally subjected to very demanding therapeutic protocols, thus emotions may divert the energy needed to strictly cope with those protocols. Some recipients may develop a psychological rejection leading to noncompliance with post-transplant protocols and graft loss. Other recipients might develop a sense of obligation towards the donor families. Concerns may also arise about social, cultural and religious background of the donor family. Distress and disappointment may originate from unmet expectations during the contact. Even small differences with imagination may cause distress. There may also be the risk of stalking, harassment and extortion. Contacts after transplantation may be difficult for recipients not yet ready to accept the new post-transplant condition and may

preclude positive interaction with the donor family. Contacts may have drawbacks because of post-transplant complications: transplant rejection, graft loss, development of infections or neoplasia. In all these conditions anonymity may protect the transplant recipient as well as the donor family [1–5].

Violation of anonymity occurs worldwide, thus the names of donors and of recipients are disclosed in the media rendering the forbidden contacts possible [6–10]. Obviously, ungoverned contacts disrupt the right to privacy and should be fought by strict application of the law.

Why break anonymity?

First of all, in a society where subjectivity prevails, anonymity should not be imposed by law. Transplant recipients and donor families should have the right to make their choices in autonomy. In principle, imposed autonomy violates the right to control personal information.

There is plenty of evidence that the majority of donor families desire contact and their bereavement is eased by seeing the results and the benefits promoted by their decision to allow organ donation from their beloved ones. Donor families have the right to receive information on the transplanted organ as a sign of recognition, appreciation and gratitude for the difficult decision to allow organ donation from their family member. It is also true that many recipients wish to personally express their gratitude to the donor family [3–5, 11].

Contacts between transplant recipients and donor families could also humanize transplantation that represents modernity and highly technological medicine. They may also provide psychological benefits to both sides. Positive stories of contacts between organ donor families and organ recipients, when reported by the media, hold the potential to highlight the most positive outcomes of organ donation and transplantation. Stories are credited with spreading positive messages and promoting organ donation.

Anonymity around the world

The World Health Organization recommends that “the organization and execution of donation and transplantation activities, as well as their clinical results, must be transparent and open to scrutiny, while ensuring that the personal anonymity and privacy of donors and recipients are always protected” [1]. Anonymity in organ donation granted in Europe [2], is a rule in Australia [3] and is protected,—as we show below—in Arabic countries. By contrast, a few countries allow contacts between organ donor families (ODF) and organ recipients (OR). Meetings are allowed in the USA [3], Israel [11], Moldavia and the Arab Emirates if both parties agree.

Table 1 Anonymity for transplantation in Europe

(A) European Union Member States (100% anonymity)	
1. CZ	Czech Republic
2. DE	Federal Republic of Germany
3. FR	French Republic
4. LU	Grand Duchy of Luxembourg
5. HR	Hellenic Republic
6. HU	Hungary
7. IE	Ireland
8. IT	Italian Republic
9. BE	Kingdom of Belgium
10. NL	Kingdom of the Netherlands
11. DK	Kingdom of Denmark
12. ES	Kingdom of Spain
13. PT	Portuguese Republic
14. AT	Republic of Austria
15. BG	Republic of Bulgaria
16. HR	Republic of Croatia
17. CY	Republic of Cyprus
18. EE	Republic of Estonia
20. FI	Republic of Finland
21. LV	Republic of Latvia
22. LT	Republic of Lithuania
23. MT	Republic of Malta
24. PL	Republic of Poland
25. SE	Kingdom of Sweden
26. SI	Republic of Slovenia
27. RO	Romania
28. SK	Slovak Republic
29. UK	United Kingdom
(B) Candidate States to European Union (100% anonymity)	
1. AL	People's Socialist Republic of Albania
2. ME	Republic of Montenegro
3. NM	Republic of North Macedonia
4. RS	Republic of Serbia
5. TR	Republic of Turkey
(C) States potentially European Union Candidates (100% anonymity)	
1. BiH Republic of Bosnia and Herzegovina ^a	
2. XK Republic of Kosovo ^a	
(D) Schengen area (100% anonymity)	
1. NO	Kingdom of Norway
2. LI	Principality of Liechtenstein
3. IS	Republic of Iceland
4. CH	Switzerland
(E) Europe black sea project on organ donation	
1. Armenia ^{b,c,d,e} , no deceased donor program	
2. Azerbaijan ^{b,d,e} , no deceased donor program	
3. Bulgaria ^{a,b,d} (EU regulation),	
4. Georgia ^{b,c,d,e} , no deceased donor program	
5. Moldova ^{b,c,d,e} , contacts possible	

Table 1 (continued)

6. Romania ^a (EU regulation)
7. Turkey ^{a,d,e} (EU regulation), (Table 1B)
80 Ukraine ^{a,c,d,e}
(F) Other European countries
1. Andorra ^{a,b}
2. Belarus ^{a,c}
3. Liechtenstein ^{a,b}
4. Monaco ^{a,b}
5. Russian Federation ^a
6. San Marino ^{a,b}
7. United Kingdom ^{a,b}
8. Vatican City ^a

^aAnonymity, ^bnon commercialization of substance of human and protections of donor and recipient origins, quality and safety regulations (Council of Europe, Ref. [3]), ^cthe European Union's European Neighbourhood Policy, ^dthey have all signed the anti-trafficking act, ^eliving donation programs

Anonymity and transplantation in Europe

The European Union (Table 1) has adopted traceability of organs in organ donation: “a system that enables the path taken by each donation to be traced, from the donor to recipient/disposal and vice versa. The procedures grant safety and quality of the organs, prevent remuneration, trade and trafficking of organs. They extend to cell donation. This system must fully respect the confidentiality of both donor and recipient” [2]. In Europe, anonymity is regulated by this specific guide [2] and by various documents pointing to the anonymity of both the donor and the recipient and remains a cornerstone for their protection [12–16]. Documents also explain the reason for anonymity:

“National laws in Europe ensure that the donor and recipient remain mutually anonymous. Not only does this avoid the creation of an emotionally difficult relationship between the donor's family and the recipient, but it allows the donor's family to grieve and gives time to the recipient living with the donated organ or tissue to begin healing in private, both physically and psychologically. Many families of donors find it comforting to be told by the transplant team which organs have been removed from their loved one and about the outcomes of the transplants. Recipients often like to hear which country their donated organ came from [17].”

In Belgium politicians attempted to rescind anonymity. One study carried out on 171 liver transplant recipients disclosed 42% opposition because of anxiety over manipulation, feelings of guilt, respect for privacy, and worry about the donor having a different background, whereas 36% wanted to change the law due to curiosity, to express

their gratitude, or to facilitate their coping process. Only 19% wanted to change the law [18].

In the Netherlands where the Dutch society seemed inclined to rescind anonymity, a study disclosed that 53% of 177 liver recipients agreed to maintain anonymity, only 13% were in favor of direct contacts, thus the need to change the rule was excluded [19]. Anonymity is also granted in the Schengen area (Kingdom of Norway, Principality of Liechtenstein, Republic of Iceland and Swiss Confederation).

In the United Kingdom anonymity is the rule as for the whole European Union to which it belonged until January 31, 2020. Exchange of data between donor families and recipients is possible through letters under the supervision of the National Health System. Donor families at the time of consent to organ donation are asked if they wish to receive a letter about the outcome of the donation. The recipient is also asked before transplantation and at the time of post transplantation discharge if they wish to write a letter of thanks to the donor family. Should they agree, they are allowed to write a letter when they feel ready to do so [20].

It is interesting that many countries in Europe, whether or not incorporated in the European Union (Table 1A–F), have similar legislation. For example, from the Black Sea Area Transplant Project on Organ Donation, we learn that Armenia, Azerbaijan, Georgia, Bulgaria, Moldova, Ukraine, Romania, and Turkey were involved in a common organ donation project. All countries in the Black Sea Group have living transplantation programs. Armenia, Azerbaijan and Georgia do not have a deceased donor program. All (a) have a regulatory framework on the transplantation and donation of organs; (b) signed the Convention on Action against Trafficking in Human Beings; (c) signed the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology

and Medicine: Convention on Human Rights and Biomedicine; (d) signed the Additional Protocol to the Convention on Human Rights and Biomedicine Concerning Transplantation of Organs and Tissues of Human Origin [21].

Anonymity in Arabic countries, Australia, Brazil and Canada

Anonymity is protected in the Arab World with the notable exception of the Arab Emirates where the law allows organ donors and recipients to meet. However, in the United Arab Emirates no one has taken advantage of this law until now (Table 2). Anonymity is safeguarded in Australia, Brazil and Canada (Table 3).

In Australia, it is currently not allowed for health professionals and Organ and Tissue Authorities to disclose the identity of donor families and recipients, and therefore to assist with direct contacts between them, but anonymous correspondence between families and recipients is acceptable. A 2017 report [3] regarding a forum, including participants from donor families, mentioned that transplant recipients, governments and organ procurement organizations debated extensively about this issue. The potential benefits of direct contact rests on the opportunity for transplant recipients to thank donor families in person, thus donor families can observe the positive impact of the donation, and enable families and recipients to learn more about one another. Potential risks were identified in the emotional impact of asymmetric expectations of donor families and recipients,

Table 2 Transplantation in the Arab world

1.	JO	Hashemite Kingdom of Jordan
2.	IQ	Iraqi Republic
3.	BA	Kingdom of Bahrain
4.	MA	Kingdom of Morocco
5.	SA	Kingdom of Saudi Arabia
6.	LB	Lebanese Republic
7.	LY	Libyan Arab Republic
8.	DZ	People's Democratic Republic of Algeria ^b
9.	EG	Republic of Egypt ^b
10.	SD	Republic of Sudan ^b
11.	TN	Republic of Tunisia
12.	QA	State of Qatar
13.	YE	Republic of Yemen
14.	KW	State of Kuwait
15.	PS	State of Palestine
16.	OM	Sultanate of Oman
17.	SY	Syrian Arab Republic
18.	AE	United Arab Emirates ^a

^aContacts allowed, ^black of deceased donor program

Table 3 Countries where anonymity is the rule

1. CA	Canada
2. AU	Federation of Australia
3. BR	Federative Republic of Brazil
4. NO	Kingdom of Norway
5. CH	Swiss Confederation
6. UK	United Kingdom

the possibility of stalking, harassment or extortion of families or recipients, the lack of protection and support such as informed consent by both parties, and professional counseling. The following suggestions were made: (a) implementation of a program of anonymous communication between donor families and recipients; (b) advice to donor families and transplant recipients regarding privacy protection, particularly with respect to social media use; (c) guidelines for those who choose to independently pursue direct contact; (d) guidelines for accidental identity disclosure; (e) possible policy changes permitting identity disclosure and facilitation of direct contact when mutually desired by families and recipients.

In Brazil [22], anonymity is the rule. A study reported that 82% of transplanted patients, 60% of patients on waiting lists, 82% of the population, and 67% of the donor families were favorable to a change in policy. However, nearly 3/4 of physicians were opposed to contacts because of the potential emotional burden on recipients at a time of demanding therapeutic regimens, but also because of possible attempts to ask for money.

Canada too grants anonymity to the donors and recipients and prohibits disclosure. Scientists are against any change; however, studies showed that 53% of them think that when both parties have a mutual desire to meet, this is acceptable [22, 23].

The USA and Israel favor contacts

In a few countries contacts are possible (Table 4). In the USA, contacts between donor families and recipients began more than 25 years ago. A study found that as many as 70% of donor families desired direct contact, and there was satisfaction by both parties when meetings occurred [24–26].

Table 4 Countries where meetings between donor families and recipients are allowed

IL	Israel ^a
KU	State of Kuwait
MO	Republic of Moldova
US	United States of America

^aThe European Union's European Neighbourhood Policy

Guidelines have been in place since 1997, were updated in 2004 and thereafter from time to time to render them suitable to the needs of the twenty-first century. Guidelines are for deceased organ donors as well as non-direct donors (Samaritan donors in Europe) and are handled with competence, efficiency and are respected by organ procurement agencies. Misuse has never been described and there is a sense of general satisfaction. The guidelines outline the reasons for contacts as well as the possible disadvantages.

The National Donor Family Council of the National Kidney Foundation analyzed the contacts (through letters, phone, direct meetings) between organ donor families beginning with records available for the year 1990. Data have been published stressing that donor families have an immediate and continuous need to be informed about recipients [27].

Pamela Alberta answered [25] the following questions: 1. Are contacts between donor families and recipients mandatory? 2. How should they occur? Who decides? Data have been published about 36 out of 37 contacts that had been facilitated in a time frame between 5 days to 15 years after transplantation. The first request had been put forth by recipients in 72% of cases. A total of 53% of donor families declared that they had always wanted—since consenting to donate—to know about the outcome of the procedure. The study indicates that contacts allowed the donor families to assess the beneficial effects of their decision to give, and the recipients to say thank you. Contacts had beneficial effects for both parties when they were well organized and well directed. Generally speaking, contacts might increase organ donations thus promoting a favorable attitude toward transplantation. “Contacts generate positive results in terms of consolation and peace for donor families as well as for recipients. For one mother it represented the triumph over a tragedy, as a mercy blessing the person who gives and the recipients” [28]. The study also stresses that in the past communications were anonymous and under strict control. In the end both parties were confused and frustrated. Indeed, recipients and donors are the key persons in the circle of life and death. Closing the path of the life-death circle (an expression used by Alkmeon of Croton) brings long-term benefits to both parties. Benefits may be magnified by the capability to meet the need for information, communication and expectations of the interested parties, among them the transplant professionals [28].

At the XIV Congress of the International Society for Organ Donation and Procurement in Geneva on September 6–9, 2017, Susan May Larson et al. [29] showed data obtained from a population of 7.2 million inhabitants, 239 hospitals and 8 transplantation centers in the years between 2014 and 2016. In those years 512 donor families exchanged letters with 1047 recipients. In the 3 years following the exchange of anonymous letters there were 50 requests to get to know each other through more direct contacts. The

study showed that the exchange of information between donor families and recipients comforts donor families and creates a more positive attitude towards transplantation per se. The findings demonstrate that the experience is positive also for recipients. However, arrangement of contacts should be well organized, adequately funded and conducted by a professional staff.

In Israel (Table 4), contacts between donor families and organ recipients are a common practice. Families of deceased donors and/or recipients and their families initiate a move to meet the other party. This is negotiated with the other family through the transplant coordinator of the National Center of Transplantation [30]. In Israel, significant changes have occurred over the years in the attitudes of transplant teams to contact the donor family and the organ recipient. At the beginning there was strong opposition. Thereafter, doubts emerged and indecision prevailed. Now enthusiasm for the procedure has rooted and is continuously nourished. There is satisfaction both in organ donor families and recipients. Contacts with a recipient have a positive effect on the donor family’s bereavement. The meetings give them the chance to check the outcome and the appropriateness and the extent of their decision. And saying thank you to the donor families helps recipients fully understand how death can spark life, raise the quality of life and erase the sense of guilt of living at the expense of another person [11, 31].

Anonymity in Italy

In Italy the issue of anonymity between transplant recipients and organ donor families is regulated by Law no. 91, issued on April 1, 1999: “Health care and administrative personnel working in organ procurement and transplant activities must guarantee anonymity of data related to the donor and the recipient”.

Two donation stories that broke anonymity have had great impact on organ donation in Italy and raised the issue of reassessment of anonymity for organ donation.

The story of Nicholas Green, killed while vacationing in Italy with his parents: his organs changed the lives of 7 people

A strong campaign was initiated by Reginald Green, a US citizen of British origin, living in Bodega Bay in California. His son Nicholas was killed by criminals on the Salerno to Reggio Calabria motorway in Italy, on September 29, 1994. Nicholas—a 7-year-old American boy—was shot while on vacation and riding in a car with his parents, Reg and Maggie, in southern Italy. That evening he met his death around 10-10.30 p. m. while sleeping in the back seat next to his

sister Eleanor. Reg, a former UK economic Journalist with the London Daily Telegraph, and Maggie, a costumer with the Pacific Opera Project in Los Angeles, were in the front seats. Nicholas was killed by Michele Iannello and Francesco Mesiano, who had mistaken the Greens' rented car—with a Rome license plate—for one scheduled to deliver jewelry that night. The child was driven to the University Medical Center in Messina in a coma where scans showed that the bullet had lodged in his brainstem. After 2 days, on October 1, he was declared brain dead. Though devastated by the loss, Maggie and Reg told the physicians that they wanted to donate Nicholas' organs for transplantation. The kidneys, liver, corneas, heart and pancreas cells were transplanted, saving the lives of five recipients and restoring sight to two others [32, 33].

Nicholas' body was brought to America in an Italian Air Force plane and he is buried at the Catholic Church of St. Teresa of Avila in Bodega Bay, a small village about sixty miles north of San Francisco. Nearby, in the coastal village of Bodega Bay, where the Greens lived, a memorial called the Children's Bell Tower was built, made of 140 bells sent by families from all over the world but mostly from Italy. The centerpiece was made by the Marinelli foundry which has been making bells for the papacy for more than a thousand years and was blessed by Pope John Paul II.

The killing caused grief all over Italy, especially because of the generosity of Reg and Maggie who had given Nicholas' organs to patients of the country where their son had been killed. Fortunately, the police carried out an immediate and efficient investigation and the criminals were arrested. One of them was sentenced to 20 years and is now free, having been given a reduced sentence for good behavior. The other criminal, who admitted to killing four other people, though always denying he killed Nicholas, was sentenced to life imprisonment.

Soon the names of the recipients, under pressure from the mass media and intense public interest, were made available. There was an unforeseen outpouring from all over Italy. Schools, parks, streets, squares, halls, fountains, museums, a literary prize, a lemon tree, an amphitheater, a coffee bar, a soccer cup for children, two school clocks, a bridge tournament, were named after Nicholas Green. Many children were given the name Nicholas [32]. There are now roughly 130 dedications. Since 2007, Reginald Green and his wife Maggie have been campaigning to render meetings between donor families and organ recipients possible if both parties agree [34, 35].

Ricky Galbiati a 15 year old student from Tirone, Italy died of sudden cardiac death while skiing

An irresistible push came from Marco a creative (industrialist) man from Lecco who had lost his 15-year-old son

Riccardo in January 2017 while skiing together. The story is the core of a book entitled "Your heart my star" that narrates the desperation and hope following a sudden death [19]. Ricky and his father Marco were skiing the morning of December 30, 2016, preparing for the New Year. Ricky, a 15-year-old student from the catering school of Casargo (Province of Lecco), followed his father on the slopes. Marco waited for his son to arrive at the bottom of the slope, but it was in vain. Ricky was found in cardiac arrest. He was transferred by helicopter to the intensive care unit of Bergamo Hospital but was pronounced dead and placed on ECMO. There was a change in skin color once circulation was reinstated. "I talked and talked again to Ricky hoping that he would hear and answer. But this was not the case" and 3 days later, cerebral death was deemed to be irreversible. "No more hope. It was necessary to pull the plug. My wife and I, who were losing our child, met with physicians dedicating their lives to saving people. In our hearts there was desperation, on the other side there were lives which depended on Ricky's death. Not just one person, but many people. We gave consent. My father arrived and I had to tell him that Ricky had died thereby breaking the link between them, a link made of complicity, protection and understanding" [36]

The kidneys, the liver and the corneas were removed and transplanted. Ricky was buried in the cemetery of Sirone, his birthplace, on January 4, 2017. His classmates and the whole small town participated. There were many appropriate speeches on life and death as well as on the absurdity of such a death, prayers and thunderous applause. Finally, Ricky was signed into the book of the dead. Part of him has entered into a cycle of eternity through the effects of his organs on the destiny of the recipients.

The story of Marco, ending with a sudden death in the age when all dreams are possible, is a tragedy which no father likes to recount. The loss of a young son enjoying sports while preparing to become a master chef is not easy to narrate. It is a kind of Greek tragedy affecting the life of a normal family, encompassing the permission for organ removal and the impossibility to metabolize the bereavement.

Therein one also learns why donor families sometimes want to know the destiny of the removed organs, that is knowledge about the outcome of an act of extreme generosity. But the law in Italy imposes anonymity which sometimes is broken. And also in this case it happened that Marco identified one of the kidney recipients. However, Marco wanted to contact all the recipients and started collecting signatures for a law of popular initiative and collected more than 40 thousand of them, a number which forced the President of the Italian Network for Transplantation to ask the National Committee for Bioethics to examine the possibility to allow permission for contacts between donor families and the recipients of the organs of their dearest dead if both parts

agree [37]. The story of Ricky and Marco Galbiati is exemplary and is potentially capable of promoting transplantation [38].

The debate in Italy on contacts between donor families and recipients

The stories of the two young boys illustrate the positive effects at different levels, including psychological ones. They have attracted the interest of television and generated long ongoing discussion in congresses and meetings devoted to transplantation. No population-based study has been performed on a representative sample of the Italian population on the question of anonymity. However we are inclined to think that places of Nicholas Green in Italy and the signatures collected by Marco Galbiati are an indication that Italians might want to break anonymity if both parties agree, under a well-defined protective network.

The opinion of the National Committee of Bioethics

On September 27, 2018 the Italian Committee of Bioethics published an opinion on “Anonymity of organ donors and receivers (requested by the Italian National Transplant Centre)” [39].

The opinion confirmed the value of law 91 but with originality foresees a possibility to establish contacts between ODF and OR. The breakthrough is based on the distinction between before and after transplantation. Before transplantation, anonymity shall be strict in order to adhere to fundamental principles on privacy, gratuity, justice, solidarity and benefits and to avoid organ trafficking. But after a “suitable period” it is ethically correct and justifiable that organ donor families and recipients can meet after signing a valid declaration of consent. Consent shall be expressed on a template valid for the whole country, to be prepared by the National Institute of Health. A third party within the body of the National Health System should control the validity of the consent.

The opinion stresses that contacts are not a right but a possibility justifiable on ethical grounds, if the procedure is followed appropriately. The suitable period of time needed before starting contacts should be evaluated by the psychologist of the transplant center to allow the recipient full recovery, avoiding negative emotional influences that could negatively impact on the transplant outcome.

Before the end of 2018, the opinion of the National Committee of Bioethics was well received by those who had supported the Campaign for allowing contacts in Italy, including the people at the Italian Institute for Philosophical Studies [40]. Carlo Petrini and Reginald Green expressed satisfaction [41]. More recently, Oliver, Moreno and Grinyo [42] analyzed the pros and cons of anonymity, including

the Italian Committee of Bioethics’ opinion, suggesting that countries willing to value the legal individual autonomy of decision, a resilience model based on confidentiality and autonomy, might represent the most suitable solution [3].

Law proposal submitted to the Italian Chamber of Deputies according to opinion of the Committee of Bioethics

A Law Proposal (No. 1941/2019) to derogate the current Italian regulation has been submitted to the Chamber of Deputies and is ready for discussion. It takes into account that anonymity, altruism, and solidarity is sometimes violated in the media so that organ donor families and recipients meet under unregulated conditions that are intrusive acts into their personal privacy. The procedure for contacts between organ donor families and organ recipients may be started 1 year after organ donation and transplantation to avoid the risks of perioperatively breaking anonymity and the risks of organ trafficking. Signing the agreement to disclose anonymity by both parties, under the supervision of a Third Party of the National Health System is the prerequisite. This law establishes a path of safe, fruitful contacts between organ donor families and recipients without the sense of guilt after the donor’s, and could confirm the donor families’ decision to donate. Although bereavement is variable—that for death of the mother is not alleviated over time (Roland Barthes, *Journal de deuil*)—a year after transplant a donor family may still be grieving, which will be comforted by seeing the outcome of their decision since the recipient should be in good health and fully recovered to normal life.

Recipients will have a chance to say thank you and will experience psychological benefits and acquire a sense of calm satisfaction and closure of the death-life circle [25, 28]. The law will also have a beneficial impact on organ donation by reducing opposition to it.

Conclusion

It is evident that the debate is destined to continue since the right to privacy is a personal act. Donors and recipients have the right to privacy. However, when both parties conflict there should be a system in place that can address the needs of the parties. And this must be sought and hopefully found [24]. In Italy, the opinion of the National Committee of Bioethics and the law proposal presented to the Chamber of Deputies indicate participation in the debate. The law respects all the values protected by the European Union (altruism, privacy, gratuity, justice, solidarity and benefits). It avoids organ trafficking. One year is the time that appears suitable to express consent. It should be enough for recipients to adapt to the burden of a demanding therapeutic

schedule, and for the family to adapt to the loss. Indeed, in the paper by Azuri, Taback and Kreitler reporting their experience in Israel [11], many contacts were established after 1 year. So Italy would not deviate from the European guidelines. Donor families and recipients have their own right to be the main characters, and their reasons matter and should be taken into account. All is possible if both agree, if both parties do not agree the process is automatically ended.

The law proposal offers a safe solution valid for all countries where anonymity is granted by law. In fact, it might be taken into consideration when both donor families and recipients decide on their own when no right of third parties is violated. It offers a solution to problems extensively discussed by donor families and recipients in Australia. In particular, it might (1) favor the development of guidelines or advice for those who choose to independently pursue direct contact and (2) ease discussions with states and territories regarding legislative or policy change permitting identity disclosure and facilitation of direct contact when mutually desired by families and recipients [5].

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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