Tens of thousands of organ donor families and recipients have communicated with each other and, in the great majority of cases, the results have been positive for both sides

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I am the father of Nicholas Green, the 7-year-old American boy who was shot in an attempted robbery on the Salerno-Reggio Calabria highway in 1994 and whose organs and corneas were donated to seven very sick Italians, four of them teenagers. The Italian people responded with all-enveloping compassion. But they did more: they directed these generous emotions into the most appropriate, *the most satisfying*, channels: in the 10 years after Nicholas died, organ donation rates in Italy tripled, a rate of increase no other country has ever come close to. Thousands of people, many of them painfully young at the time, are alive who otherwise would have died.

After 26 years five of the seven recipients are still living, although one is back on dialysis and another had a second corneal transplant. Considering that most of these people were dangerously close to death or going blind at the time of their transplant it is a remarkable tribute to the skills of the whole Italian transplant community.

In those 26 years my wife, Maggie, and I have talked to everyone who will listen—including fifty visits to Italy—to remind them how little it takes to save multiple lives.

For almost all that time I have stayed clear of speaking about Italian law, taking the view that as a foreigner it was not my place to give advice on such sensitive issues. But one aspect of the law kept nagging at me: law 91/99, which forbids healthcare personnel from giving out any information about either donor families or recipients. It was passed with the best intentions, to protect privacy, but has had some cold-blooded—even cruel—results. It effectively means that neither side knows anything but the bare minimum about the other.

Some people, it's true, don't want to know anything more: they saved someone's life or their own life was saved. Now they want to put all that behind them. But many others do very much want to know. They feel their lives are incomplete: they don't even know if the recipients are alive and it eats at them. In some cases, they feel chronically unsettled. It seems harsh treatment for people who, while suffering a devastating loss, set their grieving aside long enough to help complete strangers in desperate need.

In the United States, where I live, the institutions that oversee postoperative patient care—the 58 organ procurement organizations (OPOs) appointed by the US Department of Health—are unanimous in their belief that communication is good for the health and happiness of both sides in the great majority of cases. The procedures are carefully controlled and, before anything is done, both families have to confirm that they would like to communicate. If they do, one party sends an anonymous letter, vetted by the OPO, to the other. The second family can then decide to reply or go no further. If they decide not to go on, everything stops, however eager the first family is. If they want to reply, however, they also write an anonymous letter, it also is vetted by the OPO and the first family has the choice of continuing or breaking off the relationship.

But, instead of ending the contact, usually these families are avid for more information about each other: what can the recipients do that they couldn't do before the transplant? If they like sports what are their favorite teams? What plans do they have for the future? What is their favorite meal? All donor families are awed with the living proof that their gift had such momentous consequences. On their side the recipients yearn to express their profound gratitude: often they struggle for words but their sincerity illuminates every line. Everyone who writes or reads these letters cries.

Sometimes one exchange of letters is enough for one side or the other: their curiosity is satisfied. But for many it is the beginning of a long relationship, which evolves

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The Green family and Nicholas' seven recipients 2 years after the transplants. Photo by permission of Oggi magazine, Italy

into phone calls or even face-to-face meetings. I've been to houses of donor families where regularly the recipient family comes for Sunday dinner. One recipient I know said that, after 20 years of not hearing from the donor family, when they finally met she felt a peace she had not known for years.

I'll never forget the father of an 18-year-old who had been killed in a car accident telling me, in wonder, that he listened through a stethoscope to her heart beating in her recipient: "I think of her every day. She seems so far away," he said. "But here she was again".

At any stage one side can decide it doesn't want to go on and that is the end of it. What if the other party persists? The family wanting to break off can simply contact the OPO which then warns the offenders to stop. Since the OPO is part of the health care structure where both families get all their treatment it's hard to imagine the offending party defying that warning. In fact, American experience shows problems are very rare—and if they occur are fairly easy to deal with. Don't forget that only families who have expressed the desire to contact each other are involved. Can something go wrong? Of course. What can't? But should all those people who will be overjoyed by learning about each other, be denied that pleasure because of those rare problems?

After 30 years of this system in the United States, there are now tens of thousands of clinically-documented contacts. Against this, the opponents of change usually quote horror stories of donor families asking for money or stalking recipients or psychological problems when the two families don't like each other. Certainly there have been times when things went badly. The problem with these stories, however, is that they are almost always anonymous, and so cannot

be verified, all date from earlier than 1999, before today's safeguards were put in place, or they happened illegally and so without any safeguards at all.

Maggie and I have met all seven of our recipients and, seeing bodies that were haunted by death before the transplant now playing sports, marrying, starting careers and having babies, is a tonic without equal.

For more than 20 years I stayed silent publicly on this issue, but in 2016, at 87 years old, I decided that I might not have many more opportunities to speak out for a cause I cared deeply about. So, I decided to launch a campaign. To my surprise I couldn't find a single supporter among all the Italian physicians or healthcare executives I knew. Most, convinced by that handful of horror stories, were genuinely worried for their patients' health—by, for example, the psychological effects if the other side did not live up to their expectations. Others were afraid to speak out, not wanting to hurt their career prospects or reputations or fearing to become known as troublemakers. Some were unwilling to question a 20-year-old law. Still others were concerned that introducing a controversial issue might hurt the bigger cause of increasing organ donation rates.

Whatever the reasons, the only person willing to work wholeheartedly with me was Andrea Scarabelli from Rome, who had become a friend by being one of the hundreds of Italians who wrote to us when Nicholas was killed, and had proved time and again to be an invaluable helper in all things Italian—translator of my two books on organ donation, guiding me past the black holes that can suck in a foreigner, full of innovative ideas, unfailingly enthusiastic and so on. It was natural then that, when we set off with the entire medical

establishment indifferent or opposed, we should call ourselves Don Quixote and Sancho Panza. (He is still waiting for the governorship of the island that I promised him.)

We concentrated on the area I know best, the media. As a journalist (now retired but formerly the chief business writer for the Daily Telegraph in London and a freelance commentator for the BBC), I knew that is where I would find minds open enough to grasp the human consequences of a rigid law. So, in 2016, Andrea and I lit the fuse of a subject that had been taboo for 17 years.

We covered the full range of media. The response was far beyond our hopes, and almost all favorable. I wrote articles for publications such as *Il Corriere della Sera*, *l'Avvenire*, *The American Medical Association Journal*, gave speeches from the Alps to Sicily, came to Italy annually for several World Kidney Days, was interviewed on programs as diverse as *Uno Mattina*, *Sky TV*, *TV 2000*, *Le Iene*, *Radio Rai* and *Radio Vaticana*, and for publications ranging from *La Repubblica* to *Vanity Fair*, *ANSA*, *Il Giorno*, *Famiglia Cristiana*, *OGGI* and *La Gazzetta del Sud* etc.etc. In other words, the entire, cross-section of Italian opinion, and everywhere audiences were surprised at the power of donation and supportive.

Soon, some of the largest television programs, newspapers and magazines and some of the best journalists in Italy started to ask, "If two families, matured by suffering and sharing a unique bond, want to write anonymous letters to each other why should some bureaucrat have the power to say no?" They bombarded the healthcare authorities with questions, and soon ordinary Italians were asking those questions too.

Into this swirl of public opinion, aroused on a subject that before 2016 had seemed as dead as a dodo, stepped Marco Galbiati, an energetic and imaginative businessman from Lecco, whose beloved 15-year old son, Ricky, died and became an organ donor in 2017. In a whirlwind campaign of his own, Marco collected 50,000 signatures online to change the 1999 law.

Faced with these assaults, the National Transplant Center, which had been a strong opponent of change, referred the whole issue to the National Bioethics Committee, seen by many people (including me) as a delaying tactic. Moreover, the committee was composed of people who took pride in not being swayed by emotions, such as those of bereaved families or crowd pressure, so for them we drew attention to the data culled from the decades of experience in the United States—and it was formidable (The president of the committee even wrote to me to say they had received all the evidence they needed to make up their minds—and please not to send any more!).

After careful deliberation, the committee recommended that organ donor families should be free to write to or meet their recipients, under controlled conditions, if that was what

both sides wanted [1]. That recommendation changed everything. Professor Carlo Petrini, the National Institute of Health (ISS) delegate on the committee, said that the evidence we supplied was "a major, if not decisive" reason for the committee's decision. At last, we were vindicated. Better still, a group of legislators has now introduced a bill that would implement those recommendations.

If the people who want to know more about the other family were just a handful, and unrepresentative of the typical family, this would be a side issue. But it is not. This is what Alexandra Glazier, Chief Executive Officer of New England Donor Services, an OPO responsible for organ donation in six American states with a population of 14 million, says: "A recent review of our data indicates that about 52% of donor families will connect with a recipient, either by receiving a communication from or sending a communication to, within the first 2 years of their loved one's organ donation".

And here is what the CEOs of some of the largest OPOs from widely different parts of the United States say: "Our foundation's experience with donor family and recipient communication has been overwhelmingly positive for all involved," says Kathleen Lilly, Executive Vice President of LifeLink Foundation, which covers areas as diverse as the modern cities of central Florida, rural portions of Georgia, the high-class tourism of the U.S. Virgin Islands and Spanish-speaking Puerto Rico.

"Donor families have only one request and that is that we save as many lives as we can with their gift. Those who meet the recipients get a chance to see that promise fulfilled," says Kevin Cmont, CEO of Gift of Hope, whose area covers 12 million people and 183 hospitals, including Chicago, home to two hundred thousand people whose families came from Italy.

"The ability to exchange letters between donor families and recipients is profoundly healing and therapeutic for both parties, and often leads to in-person meetings and long term friendships between donor family members and recipients of their loved one's organs," says Kevin O'Connor, Life Center Northwest, whose territory includes states in the northwest of the United States and Alaska.

All that experience is difficult to argue against, isn't it? I'm aware that what works well in one country cannot be imported wholesale into another. But I refuse to believe that Italian grief differs significantly from American grief.

In view of all this I was delighted to see your Journal had the foresight to publish a new paper on the subject because it brought together not only physicians but eminent names from bioethics and the law under the title "Legislative Proposal in Italy to Facilitate Contact between Deceased Organ Donor Families and Transplant Recipients" [2] (though I have pointed out to the authors that deceased organ donor families cannot contact anyone: they are deceased!).

I am therefore very sorry to say I was greatly disappointed in the report itself. First, it pays only passing attention to the US experience, the only large collection of data in the world on contacts between the two sides, and makes no mention at all of the crucial role all that experience played in the National Bioethics Committee's surprise decision.

Second, it says nothing about the media blitz of 2016 that started the whole awakening of interest in a subject that for ordinary Italians at the time scarcely existed. For any other country considering opening up communications between families, an understanding of the role the media can play is essential.

Third, its conclusions are hesitant: 'we are inclined to think that ... Italians might want to break anonymity, if both parties agree, under a well-defined protective network.'

I have left the most serious blemish to the end. "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," it says. That's wrong. The authors have equated contacts, which include all forms of communication, with face-to-face meetings—and that mistake changes the picture radically. Face-to-face meetings are a big step above letter writing and most families don't want to go that far.

But a survey from 2019 by the Association of Organ Procurement Organizations, which represents all 58 organ procurement organizations, shows that the 48 OPOs which replied had forwarded 24,000 letters between transplant families in that 1 year alone. And that excludes not only all letters sent directly between the two sides after the first year when the transplant occurred and they are free to write to each other without going through an OPO, but also any phone calls, emails or text messages too, the modern way of communicating [3].

Scanty? No way.

Still, the paper came down on the side of enlightenment which, if implemented, will ease a lot of heartache for transplant families and I'm grateful for that.

As I was writing this article, the Deputy Minister of Health, Dr. Pierpaolo Sileri, spoke out not hesitantly but unambiguously. I have attached his full statement at the end of this article but the key is this phrase: "The liberalization of contacts between recipients and donors is a gesture of humanity and civilization." [4]

I am so glad to hear it. 4 years ago, as the Man of La Mancha put it, it seemed an impossible dream.

Reg Green.

Statement by Dr. Pierpaolo Sileri, Italian Deputy Minister of Health, September 23, 2020.

"The liberalization of contacts between recipients and donors is a gesture of humanity and civilization, a dutiful act, which must find its rightful place in a modification of the current legislation, law 91/99. This battle can and must be continued, creating a structured system that, beyond the law, accompanies recipients and donors in the elaboration of mourning. I want to thank Nicholas' family once again, who without trusting their neighbors and willing to contribute to our emancipation as individuals, would never have pursued the path of giving and the liberalization campaign. It means having your neighbor at heart and waging a battle like Don Quixote, as Nicholas' father Reg Green recalls. Together we are stronger and more human, as Nicholas and his family taught us."

Compliance with ethical standard

Conflict of interest I have no conflicts of interest of any kind.

Ethical approval It does not contain any research involving either animals or humans. My only interest is to educate readers about organ donation and its results.

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