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Nicholas Green Heart

In a small restaurant in Rome a few months ago our table was next to that of a singularly beautiful woman, vaguely familiar. "She's a television personality," my friend, Andrea, told me, "and is sensitive to human issues." It was Alessia Marcuzzi.

I have a good cause too so, when we got up to leave, I excused myself for interrupting her talk with her handsome companion and introduced myself as the father of seven-year old Nicholas Green, an American boy who was shot in an attempted carjacking on the Salerno-Reggio Calabria autostrada.

That was twenty years ago but I was sure she would remember because my wife, Maggie, and I donated his organs and corneas to seven Italians, four of them teenagers, and I have yet to meet an Italian who was an adult at that time who does not remember the upsurge of emotion from your generous-hearted countrymen. She did remember, said some kind things and we left.

That night, however, she put an item about our meeting and Nicholas' story on her Facebook page and included Aido's webpage address. By the next day 30 000 people had said they 'liked' it. Seven hundred of them sent in a comment, most of them expressing passionate support for organ donation, and 1600 thought the story was worth putting on their own Facebooks, potentially reaching hundreds of thousands more. Postings on the site around that time were averaging about one thousand 'likes'.

So, yes, it's true, we all know it, organ donation is normally too remote a subject to capture widespread attention. It is my observation, however, that once people feel a personal connection, once they see an interesting human face in it, organ donation can become of riveting interest. This is not surprising: every one of us could need a new heart, kidney or some other vital organ or new tissue, such as skin to cure excruciating burns or bone to straighten spines. Equally, any of us could be a donor. It is truly a universal subject. Add in that it is also a story of life coming out of death so, when told as a human story, how could it be anything other than compelling?

Some people have no choice about being interested: they are on a long and lengthening waiting list, waking up every day thankful that they are still alive but with growing anxiety as they wait for someone completely unknown to them, devas-

tated by having just lost someone they love, being willing to put their grief aside long enough to save the lives of people they never met. It is an agonizing wait, made worse by being completely helpless to speed up the process. Every time the telephone rings their hopes soar, every time it is not the call they were waiting for the darkness closes in.

The overwhelming majority of people in most developed countries say they are in favor of organ donation. Yet donated organs are scarce everywhere. Partly this is because demand has increased so rapidly, as physicians have found ever more cases where a donated organ is the preferred, often the only, cure. But it is also because the setting in which the decision has to be made is so forbidding.

Families faced with the decision become aware that at the moment they say 'yes' they are also saying goodbye. No more clinging to hopes of a miraculous recovery or fantasies of setting off on a favorite walk together. There are also many twists of the knife when trying to decide. On that last day I went into the small room to see Nicholas one more time and my heart leapt: there he was in bed, breathing regularly, his chest gently rising and falling. "He's getting better," I thought excitedly. "I must tell someone right away." And then a split-second later the crash to earth as I realized it was simply a clever machine breathing for him.

He never regained consciousness. I can still see quite clearly the doctors in that sunlit room in Messina saying, gently, "We have bad news for you. We can find no brain activity." We sat there, holding hands, not talking. I tried to absorb the thought that I would never again hear him say "Goodnight, daddy." Then Maggie, thoughtful as always, said quietly, "Now that he has gone, shouldn't we donate the organs?"

The thought was inspiring. For the first time since he was shot, there was a glimmer of light in the blackness. Something good could come out of this mindless violence after all. I said "yes," we told the doctors that is what we wanted to do and went back to the hotel to pack. It could not have been simpler. Of course, it doesn't take the pain away: after twenty years I still think of Nicholas several times a day and always with a sense of an irreparable loss. But it has put something on the other side of the balance. And of all the hundreds, perhaps thousands, of donor families I have met since then, I can scarcely think of one who regretted it. But, though it was as clear to those families as it was to us that this was the right thing to do, for many people it is much harder and made harder still because brain death is sudden death. They have no preparation for it and arrive at the hospital to find a loved one who was in perfect health a few hours before is now dead or dying. They may be angry or too distraught to understand the options. Perhaps a child drowned or was hit by a car coming home from school because of what one parent considers the carelessness of the other. Perhaps there has been a bitter divorce and the two sides have not spoken in months but now have to discuss a hypersensitive subject neither of them has ever given any serious thought to. Perhaps just one family member is adamantly opposed and, at a time like this, the rest are unwilling to argue. There is no time to deliberate: the decision must be made there or then or not at all.

So many people say no and regret it for the rest of their lives, realizing only later that they have turned down the chance to rescue several families from the devastation they themselves are going through. Only then do they see that they had let slip through their hands what is probably the best opportunity they

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will ever have to make the world a better place for others. Normally in Italy the two sides never meet. In our case, however, where the publicity was all-enveloping, the recipients were known within days and we met them all with, I think, the overwhelming approval of Italians of all kinds. Having met them, and learning how close to death some of them were and knowing what would have happened to them, I know that if we had simply shrugged off their problems as none of our concern, Maggie and I could never have looked back without a deep sense of shame at having turned our backs on them.

And so, the most fundamental of all changes that would improve donation rates is for people to think about organ donation when they are calm and can discuss it thoughtfully with their families. To do this we must make an all-out effort to make the public feel at home with the idea of organ donation so that it ceases to be something distant or strange or something to be thought about later and instead becomes as natural as making end-of-life decisions while you are still quite healthy.

There are many ways to do this but for me, the most effective way is through personal stories. Everyone with any connection to transplantation has a unique story. I believe we should all – and especially donor families and physicians – be telling those stories. For anyone who wants to work with me, I will do whatever I can to help.

The results of transplantation, though they vary by different organs, surprise most laymen. In the United States 90% of heart recipients are alive one year after the operation, 75% after five years and 55% after ten. Given that all these people were terminally ill, some on the threshold of death, and that some will die of unrelated causes, it is an amazing record.

Oh, and by the way, speaking to beautiful strangers in restaurants can also produce surprisingly good results.

Reginald Green

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Reginald Green has written two books and produced a 12-minute documentary film, all of which have been translated into Italian. He has offered to send any of them electronically without charge to anyone who contacts him at rfdgreen@gmail.com. His website is www.nicholasgreen.org.

Why transplant matters

Every night, somewhere in Italy (as all over the world) an interventional cardiologist wakes up and goes to the cath lab, to open the coronary arteries of a patient suffering from an acute myocardial infarction. This cardiologist is proud of being able to deliver this highly effective treatment – and is right. The same cardiologist is much less enthusiastic if and when he or she should go to the hospital in the middle of the night to perform a coronary angiography in a 55-year brain dead man – and in this case is wrong, because excluding coronary artery disease in a potential heart donor is at least as life-saving as opening a blocked coronary artery... The only difference is that in the case of the potential organ donor the cardiologist performing the angio does not know the ultimate beneficiary of his/her work. Similarly, a noninvasive cardiologist is generally ready to study with a complete and sophisticated echocardiographic exami-

nation a patient with, say, suspected endocarditis, or a heart failure patient with 125 ms QRS duration who is under evaluation for cardiac resynchronization therapy. But it happens to obtain from the same cardiologist only approximate and low-quality echo reports in potential heart donors, although everybody would agree that a good echo is very important along the organ retrieving process. This is for saying that, for a transplant program to be effective, how doctors work around potential organ donors is as important as promoting societal attitude in favor of donation.

I have worked since 1990 at the Heart Failure and Cardiac Transplant Program of the Niguarda Ca' Granda Hospital Cardiac Dept., of which I am now the director, and just a few months ago we celebrated the discharge of our 1000th heart transplant recipient. Moreover, when he was 41 years, my brother, a brilliant professor of physics and theory of probability at the Milan University, died due to a cerebrovascular accident, and thanks to his wife's willingness he became the donor of many, including a heart transplant recipient of whom I took care for almost 20 years.

So it has been a pleasant surprise for me to receive this letter by Mr. Reginald Green, and I am glad to offer it to all the readers of the *Giornale Italiano di Cardiologia*. Mr. Green's approach is very personal. He and his wife cannot be enough appreciated and thanked for having been able to transform a personal tragedy into an extraordinary opportunity for thinking about the value and the meaning of other individual lives and histories. As doctors, for being in favor of organ donation, we should not need to know all of them one by one, and most of all we should avoid the risk to apply to them our personal or societal value scale. But knowing *some* of them can be extremely useful for reminding us that here they are (individual, personal histories of dying, living, suffering and hoping), behind both the donors and the recipients. Although anonymized, organ donation and transplantation are never anonymous.

In the patient's perspective, medicine is always just and exactly made (should be) for individuals – for me, my mother, my husband... whatever. And in theory, when a doctor sees a patient, he or she should be focused just and exactly to do all the best for him/her – but we know that this theory does not work anymore without taking into account money, human resources, sustainability, cost-effectiveness, and so on. Moving from a purely individualistic (the single patient and his/her doctor) to a wider, social perspective is not all bad, but obliges all of us (we, the people – not only the doctors) to choose our priorities and declare what we think are the best options.

While kidney transplantation is not under discussion (because, taken together, it is also cost-effective in the long term when compared to dialysis), and liver is nicely parsimonious (it may serve two people with one donor), heart is the snob, choosy, elusive organ... Talking seriously: the concept that heart transplantation is costly and "epidemiologically irrelevant" comes sometimes to surface in the cardiologists' community, and does no good if it stands without balance.

When we treat all our post-infarction patients with the recommended pack of drugs, since the benefit has been statistically demonstrated in large patient cohorts, we are inclined to believe that we are doing a little good for all those people, while in fact we are treating most of them for "saving" (from a heart attack, not necessarily from death) one – or few – single patient(s). The others (those that would anyway have a heart attack, and those who would not independent of treatment) plus

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that patient, taken together, make the NNT (Number Needed to be Treated) for a given amount of time to avoid one event. So, by the end, medicine becomes again a matter for individuals – we just are not able to identify *ex ante* the beneficiary.

The opposite happens with heart transplantation that if guided by appropriate, equitable and shared allocation policies is an extremely well targeted therapy. Both patients and physicians know exactly how big a difference it can make to get it, or not.

Maybe that with the help of Mr. Green's words we could correct this sort of presbyopia that makes it more difficult for us to see what is closer – the individual, the patient. Keeping all the good that the so-called EBM (evidence-based medicine) made for our methodology, practices, and, by the end, for patient outcomes, we should at the same time be able to recover the ancient art of caring for individuals, if we want to understand the values of transplantation. On the other side, a few issues challenge societal values, and need an agreement between healthcare organizations, professionals, patients, and the citizens' community, more than transplantation: shared

principles, based on both ethics and knowledge, should be translated into regulations and protocols regarding organ donation and allocation priorities, which should be strict enough to make it clear how to adhere to them, and flexible enough to adapt to incorporate new discoveries and opportunities.

Thus, transplant medicine is an extraordinary school of both individually-targeted and socially-oriented medicine, whose teachings are useful in other complex, borderline conditions which face our professional lives: e.g. decision making in emergency conditions, in the intensive care setting, regarding end-of-life issues and allocation of scarce resources.

As doctors, I think we have the responsibility to work to refine all the facets of this precious stone, including citizens attitude, healthcare organization, scientific advance, and personal commitment –whatever our role. Because transplantation may matter – it matters, indeed – for all of us.

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