

The miracle of life after death

A third of all organ transplants in the world are carried out in Europe

It was 6 o'clock in the morning when she was woken by the phone. She barely had the strength to answer it; she did not yet know that that call was going to change her life for ever. Just a few hours later, she was already in hospital awaiting the results of compatibility tests to see whether she could receive a kidney. Four days later, she was back home, with a new kidney inside her and her whole life ahead of her. The Irish journalist, **Regina Hennelly**, was just 24 years old when a routine medical check-up revealed that her kidneys were failing. Within a few months, she was on daily medication and having to undergo dialysis, a treatment that robbed her of 10 hours of her life. Her quality of life went seriously downhill; she lived in constant fear, watching her diet scrupulously: 'A banana can kill you.'

'When your renal function drops below 20% and your chances of surviving the next five years are not at all encouraging, that's when they put you on the waiting list.' And so it was that two years and seven months went by, her health deteriorating little by little, until one day fate matched her with someone who had passed away and whose kidney turned out to be compatible. Out of the blue, this event turned her life around. Her smile returned while she thought about the miracle of the gift of life from someone who had just died.

'I woke up and the first thing I did was check that the tubes were gone from my body. In their place, there were just 36 staples. Then I knew the transplant had been a success. I know it isn't a permanent cure, but it's given me another fifteen years,' she explained to a group of health journalist colleagues and me, assembled last week at a subject workshop organised by the European Commission in Brussels to showcase the state of transplants in Europe.

Similar stories happen every day, thanks to an effective health system that works tirelessly from the identification of the optimal donor for each serious case on the waiting list through to the transplantation of the organ under the best conditions. As one family is mourning the loss of a loved one, another family elsewhere receives the call that brings them back hope, the prospect of a new chance to live without illness.

Just a few minutes separate the absolute despair of some and the spontaneous hope of others. It's an experience shared by all the members of the **Association of Relatives of Organ Donors (AFADA)**, the only one of its kind in Spain, created in 2002 for the recognition of donors. This very June, the association unveiled a monument in tribute to donors, which can be seen in the grounds of the Orthopaedic Hospital of Granada. Not in vain, for Granada is the Spanish province with the greatest solidarity in organ donation, an admirable fact, much credit for which is surely due to Manolo Burgos and Blas Baquedano Fernández, veterans in coordinating intra-hospital transplants.

Belgium holds an annual celebration in honour of all anonymous donors. Their relatives come together and pay tribute to their loved ones. They share experiences. 'There is nothing quite like receiving a hand-written letter of thanks from the person who received a transplant organ from our daughter,' acknowledges Lia Van Kempen, founder of the [Belgian] association *Nabestaanden van donoren* (NAVADO) and mother of Kelly, who died when she was eight years old, in a domestic accident in February 2000. This 'thank-you letter' gesture is also an option in Spain, thanks to the collaboration of the health centres, which ensure that the anonymity of both parties is maintained, as required by law.

You don't have to die to give the gift of life

Some patients don't need to wait for the death of a compatible donor, because in certain cases a living donor decides to give them one of their kidneys, as happened to the brother of Sofía, an official at the European Commission who told her story at the same workshop on organ donation in Brussels. Sofía didn't hesitate to travel to her country of origin for the operation in July 2008. 'I felt it was my obligation, to me it's an act of love and nothing more. I don't feel like a hero. I never had any doubts, although in my interview with the psychologist they did ask me to reconsider, in case my daughter needed me in future. I believe we can't let the future paralyse us in the present. We'd never do anything if we worried about what the future might bring.' Today, she leads a completely normal life with a single kidney, as does her brother; the only reminder is the scar on her body, which she sees as 'a work of art'.

Over ten years, the number of live donors in the EU has increased by approximately 86%; deceased donor numbers have increased by about 18%. This is not the same everywhere. In our country, donations from the deceased are still much more common than paired or pooled donations or donations among relatives. Still, Spanish altruism and solidarity mean that our country tops the leader-board for the number of kidney transplants in Europe, with an annual average of more than 54 transplants per million inhabitants - a total of 2 522 kidney transplants in 2013, out of the 24 000 such 'miracles' that occurred in Europe last year.

The Spanish transplant model, which is in its 25th anniversary year, is serving as an example to various countries. For example, in the region of **Tuscany alone, annual donations doubled following the introduction of the Spanish model**, based on the implementation of procedures and ongoing training of the Transplant Coordinators Group and those in charge of it, as well as maximum coordination at all levels of health administration.

However, regrettably, not everyone who needs a transplant finds a compatible donor. In Europe alone, there are currently 70 000 people waiting for a kidney, 8 500 need a liver in order to survive, 3 850 need a heart, 2 200 a lung and 1 600 a pancreas. A total of **86 000 European patients remain on waiting lists**, according to Council of Europe figures¹.

12 European patients die every day while on waiting lists

Nearly 6 000 deaths a year may seem a high figure, but what is certain is that the figure varies between 15 and 30% and is reducing year after year, thanks to the good work of the teams of transplant coordinators at the Hospitals, who are succeeding in getting more people to agree to donate. These professionals play a key role, as is clear from the European Union's Action Plan on Organ Donation and Transplantation.

Another reason is that organs are being transplanted from ever-older patients; for example, it is now possible to transplant 90-year-old livers or 75-year-old kidneys.

South Alliance for Transplants (SAT), a unique voice on organ and tissue transplants for southern European countries

In response to Member States' interest in cooperation, a forum called South Alliance for Transplants (SAT) was set up two years ago. This network of southern European countries with similar systems of transplant management is intended to enable countries to exchange experiences with a view to making their transplant systems more efficient and accessible, maximising cooperation, and boosting living unrelated kidney donation. It also aims to work with a single voice in implementing European Directive 2004/23/EC of the European Parliament on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells.

The network is led by Spain, Italy and France. Recently, Portugal, the Czech Republic and Switzerland also joined, because, in the words of Rafael Matesanz, 'they share our values'. Matesanz is Director of the Spanish National Transplant Organisation (ONT) and the driving force behind the European ACCORDⁱⁱ project (*Achieving Comprehensive Coordination in Organ Donation throughout the European Union*), which was launched in May 2012 to push ahead, over the course of three years, with providing recommendations on the design and management of live organ donor registries, with the purpose of achieving 'transplant self-sufficiency in each country'.

To meet the need for transplants in Europe, it would be necessary to perform 170 transplants every day; the current rate is 80

One issue currently occupying SAT is how to improve donation rates. In Europe, about 20 per cent of relatives still do not consent to the donation of organs or tissue from their loved ones, regardless of the deceased donor's opinion in life.

It isn't a matter of religion; all religions support organ donation. Nor is it mistrust of the system used to select transplant recipients, as this is very rigorous and is known to be based purely on medical criteria. It's simply that it can be difficult for people to understand the concept of brain death, when the brain is no longer alive, and breathing is being maintained only artificially, in order to keep a blood supply to the other organs. A diagnosis of brain death requires prior confirmation by three specialised doctors, who carry out more than 15 tests on the prospective donor to verify that they have indeed died. Perhaps just saying the patient had died, without going into more detail about the irreversible loss of brain function, would make the process simpler. This remains a matter of debate among professionals.

85% of families in Spain say yes to donation once they have talked with the Transplant coordinator. The percentage withholding consent has remained stable at around 15% for a number of years, and according to Dr Rafael Matesanz, achieving a reduction in this figure is a very complicated matter.

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ⁱ This figure relates to patients in the EU plus patients from Iceland, Norway and Turkey. Data as of 31 Dec 2013.

ⁱⁱ Funded by the European Commission : <http://www.accord-ja.eu/>
<http://ec.europa.eu/chafea/projects/database.html?prjno=20112102>