

More organs for seriously ill people

Politicians, scientists, doctors and journalists discussed how to help more people in urgent need of a kidney, liver, heart or lung transplant at a workshop in Brussels. The best solution so far appears to be the 'Spanish model', where potential donors are identified as early as possible, their relatives are informed in a sensitive way and the transplantation process is implemented efficiently. New research is a cause for optimism, but it will be a long time before artificially produced organs are available.

Felicitas Witte, doctor and science journalist

Primary-school-aged Kelly wanted to bother her sisters – a short time later she was dead. Apparently bored, she knocked at her sisters' bedroom doors. "I haven't got time. I have to do my homework," was the answer from one of them. "I can't right now," was the response from the other. Feeling peeved, Kelly ran down the stairs. The next thing Kelly's mother and sisters heard was a dull thump followed by loud yelling. "I ran to her straight away and asked where it hurt – I thought it was nothing serious," remembers her mother. Seven years after the event, the shock of what happened is still written on her face. "When Kelly made only a vague movement with her head and her pupils started to dilate to an enormous size, I realised that something terrible had occurred." Her neighbour, an intensive care nurse, urged her to take Kelly straight to hospital. She survived the ensuing seven-hour operation, but the pressure on her brain caused by the cerebral haemorrhage had already damaged her nerve cells beyond repair. Her heart was still beating, but she was brain dead. Her parents had to say goodbye. Yet, in a way, Kelly is still alive, as her organs were donated, saving the lives of three children and a man. "That helped us in some way to bear the terrible shock," says Kelly's mother.

More than 63 800 people in Europe are currently waiting for an organ, including 1 165 in Switzerland at the end of 2012 – 8.5 percent more than the previous year. "Never before have there been so many," according to Franz Immer, cardiologist and director of Swisstransplant. Since January 2013, 50 people have died in Switzerland waiting for an organ, whilst, in the rest of Europe, the figure is almost 4 000 – more than 10 per day. "Transplantation has become the victim of its own success," says Axel Rahmel, medical director of Eurotransplant in the Netherlands. "Even though, last year, more than 30 700 organs were donated in Europe, that's not enough to cover rising demand, because people are living longer and are ever more likely to suffer from chronic diseases."



Franz Immer, Herzchirurg und Direktor von Swisstransplant: «Mit unserer Kampagne konzentrieren wir uns

Franz Immer, heart surgeon and director of Swisstransplant: "We are focusing on hospitals and clinics. Because those are the places where the desire to donate is translated into an actual donation."

No evidence that publicity campaigns work

Recently in Brussels, politicians, doctors, scientists and journalists discussed what could be done about the lack of available organs. The upshot was: there is no one right answer.

Various approaches are needed: better organisation, new medical techniques and the use of new media. The most surprising finding was that "awareness-raising campaigns achieve nothing," according to Rafael Matesanz, director of the Spanish national transplant organisation (ONT). "Apart from a few anecdotal reports, there is no evidence in the medical literature that publicity of this kind makes people any more likely to donate or increases donation rates", he says, adding that there is so much advertising in the media that those for organ donation tend to be overlooked. If there are negative stories about organ donation in the media or scandals are uncovered, as currently in Germany, where transplant doctors have allegedly manipulated data about patients on waiting lists, this can lead to a real decrease in the willingness to donate. For example, in Germany in 2012, when the scandal broke, there were 12.8 percent fewer organ donors than the year before. Matesanz modestly points to the transplantation figures in Spain, which is top of the league when it comes to organ donation: in 2012, 1 643 deceased people donated their organs, equating to 35.1 per million of population (ppm) (see figure page 3).

Switzerland, with 12.5 donors per million, is far behind. But Spain was not always leading the way. In the late 1980s, Spain, with 14 donors ppm, was just below average by European standards. The fact that, today, the rate is more than twice as high is due to the introduction of the Spanish model of organ donation and transplantation. "Our model is not based on traditional campaigns but on systematic organisation," says Matesanz. All transplantation activities are organised in three independent but connected networks, at national, regional and hospital level. In each case, the key figures are the transplant coordinators in the hospitals, often intensive care doctors, who identify potential donors at an early stage and initiate a potential donation. Ongoing documentation and internal and external audits ensure quality. "One of the most important elements is good training for all those involved," says Matesanz. Since 1991, more than 11 000 transplant experts have been trained in Spain. They learn, among other things, how best to communicate with relatives.



Rafael Matesanz, director of the Spanish National Transplant Organisation (ONT): "Apart from a few anecdotal reports, there is no evidence in the medical literature that publicity makes people more likely to donate or increases the rate of donation."

Donation figures rise after the introduction of the Spanish model

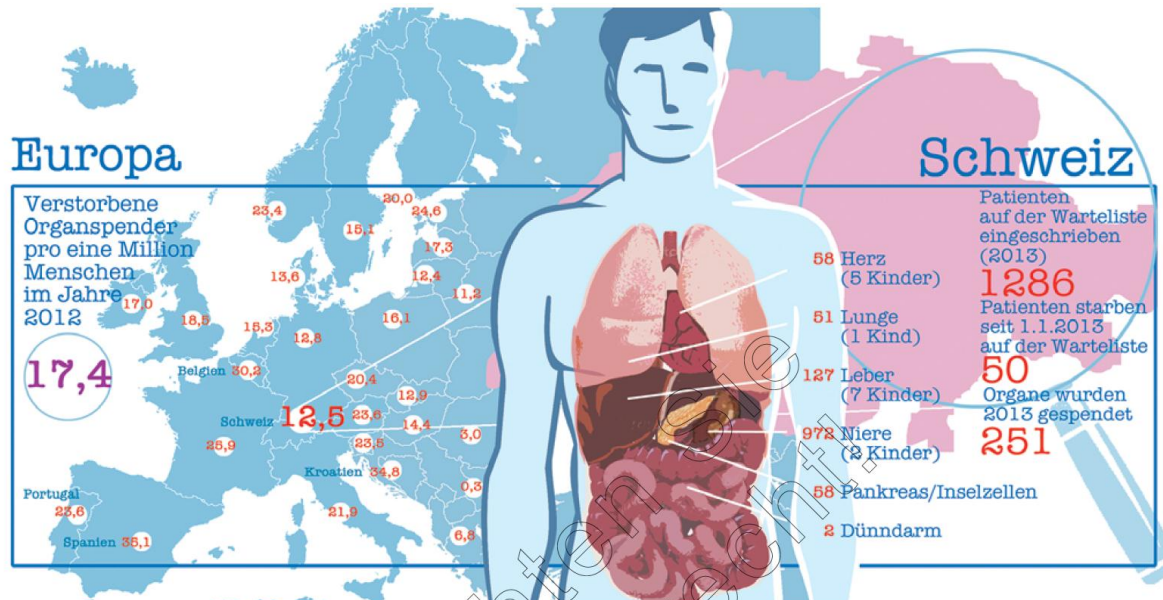
A positive attitude to transplantation among the public can be achieved only in close cooperation with the media, according to Matesanz. In this regard, the ONT is available to answer questions around the clock, and regular meetings are held with journalists. "Our transplantation experts in hospitals learn to make clear statements and to communicate them," says Matesanz. Thomas Breidenbach, director of the Deutsche Stiftung Organtransplantation Bayern (DSO- German Organ Transplant Foundation, Bavaria), wants to achieve much the same thing with the EU-funded FOEDUS programme. "We are currently drawing up an international strategy on the best way to inform the public," he says. "We want to avoid or at least mitigate the negative image of transplantation – even if, every now and then, there are scandals, such as the one in Germany."



Thomas Breidenbach, Direktor der Deutschen Stiftung Organtransplantation Bayern (DSO): «Mit Facebook

Thomas Breidenbach, director of the DSO (Bavaria region): "Facebook and Twitter are perhaps a way of getting more young people to think about the subject."

Some countries have restructured their organ donation system in line with the Spanish model – successfully. In Croatia and Portugal, for example, transplantation rates rose by 37 and 54 percent respectively between 2006 and 2009. The European Union is now supporting several further training programmes, such as the European Training Program on Organ Donation ETPOD, the ACCORD (Achieving Comprehensive Organ Donation in the EU) programme or DONOR Action®, an international joint venture with the aim of combining existing knowhow so that hospitals can optimise their procedures. However, donation rates still vary widely around Europe (see figure).



Spanien ist Spitzenreiter bei der Organspende. Nach Einführung des «spanischen» Modells für Organspende und Transplantation» stiegen die Spenderzahlen auf mehr als das Doppelte. Auch in anderen Ländern, die das Modell übernahmen wie Portugal oder Kroatien, wurden danach mehr Organe gespendet.

Europe

Deceased organ donors per million population in 2012: 17.4

Switzerland

(Figure, page 1030)

Patients on the waiting list (2013): 1286
 Patients on the waiting list who have died since 1 January 2013: 50
 Organs donated in 2013: 251
 58 patients waiting for hearts (5 children)
 51 for lungs (1 child)
 127 for livers (7 children)
 972 for kidneys (2 children)
 58 for pancreases/islet cells
 2 for small intestines

Spain is out in front when it comes to organ donation. Donation rates there more than doubled following the introduction of the Spanish model of organ donation and transplantation. More organs were also donated in other countries where the model was adopted.

This could be connected to the different legal rules. For example, in Belgium donation rates doubled within around two years after the introduction of the presumed consent system, whereby relatives have to explicitly object to the donation if the deceased did not explicitly make their wishes known when alive. In Belgium and Austria, where everyone is assumed to be a potential donor unless they expressly opt out, donation rates are twice as high as in Germany or Switzerland, where the explicit consent system applies, where organs can be donated only if the donor, when alive, or the relatives after the donor's death explicitly consent. "But whether there is a cause and effect relationship between the legal situation and the higher rates is difficult to prove," says Axel Rahmel. Since 1 November 2012, the health insurance funds in Germany have been obliged to ask their members every two years about their position on post-mortem organ donation, from the age of 16 onwards. "It's a good approach," says Axel Rahmel. "The important first step is for people to discuss organ donation with their family." Head of Swisstransplant Franz Immer also agrees with the German approach. "The only question is how and where the responses are collected. In any event, it's very expensive in administrative terms."



Axel Rahmel, Medizinischer Direktor von Eurotransplant in den Niederlanden: «Dass in Deutschland alle

Axel Rahmel, medical director of Eurotransplant in the Netherlands: "It's good that, in Germany, all health insurance policyholders are asked about whether they wish to donate their organs after death. The important first step is for people to discuss organ donation with their family."

In March 2013, a move in Switzerland to switch to the presumed consent system was rejected. Instead, Swisstransplant started a national poster and information campaign in mid-September. "We are focusing on hospitals and clinics," says Immer. "Because those are the places where the desire to donate is translated into an actual donation". Dentists could also play an important role here: "People need transparent, serious information about organ donation – and that could include information material in waiting rooms."

Growing organs using bio-engineering

The new techniques at the workshop presented by transplant surgeon Jacques Pirenne of the Louvain University Hospital in Belgium sound exciting. For example, for years donor organs awaiting transplant have been kept cool in simple ice boxes. However, cold perfusion of kidneys means that they are less likely to be rejected. A normothermic ex-vivo lung perfusion can mean that previously untransplantable lungs can indeed be transplanted. "The indications are far less strict than they used to be," says Pirenne. Under the looser indication system, transplants can be carried out today even if the donor is overweight, after a heart-lung resuscitation of more than five minutes or where the donor is older than 65 years. Pirenne recently transplanted the liver of a 90-year-old. Crossover transplantation can help in the case of HLA incompatibility, and, in the area of liver transplants, the tissue from a liver can be shared and used to save the life of two patients. However, xenotransplantation from pigs or chimpanzees did not live up to its promise. Researchers want to use new genetic techniques to better understand and tackle organ rejection. Organ bio-engineering is a real 'hot topic' according to Pirenne. For instance, detergents can be used to remove all cells from a donor organ, leaving just the structure, made out of connective tissue. Cells are then taken from the recipient and attached to the organ, so that a new organ grows. In this way, a working group led by the

surgeon Paolo Macchiarini at the University of Barcelona built an artificial trachea, grown in a patient with end-stage bronchomalacia. The technique was tested in animals for kidneys, livers and hearts, reported Pirenne, but, so far, it does not yet function like a real organ. Neither has it yet been possible to produce new organs from stem cells.



Eine «ganz heiße Geschichte» findet Jacques Pirenne das Organ Bioengineering. Mit Detergenzien werden

Organ bio-engineering is a real 'hot topic' according to Jacques Pirenne. Detergents are used to remove all cells from a donor organ, leaving just the structure.

Perhaps, until then, the new media such as Facebook, Twitter, Youtube and the like can help. Facebook introduced a new "Share your donor status" option in 2010 and, just one day later, more than 50 000 users had added it to their profile, leading to 13 054 registrations. "You can share the information among friends, which perhaps yields much more than advertising to the public in general," says Thomas Breidenbach of the DSO. In Canada, a young woman in urgent need of a lung transplant tweeted the singer and teen idol Justin Bieber, who forwarded the tweet to his 16 million followers, and just a few days later more than 1000 people had registered as potential organ donors. "We will not know for a few years whether the new media really do increase donation rates," says Breidenbach. "But perhaps it is a way of getting young people in particular to think about it."

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