

Organically European

Living donors are happier and live longer

Every day, ten Europeans die waiting for an organ. There are currently 64 thousand patients on waiting lists in Europe, fifty thousand of whom are waiting for a kidney. The number of donors continues to be well below the number of people urgently needing an organ, which is why the European Union is now addressing the issue.

GITTA IPOLYI-TOPÁL

The complexity of the subject is revealed by the fact that, while it requires cooperation between several branches of medicine, some astounding transportation issues also need to be resolved, not to mention the ethical, social and cultural aspects that must be taken into account. Moreover, everything needs to be agreed with the families of people who had been declared brain dead.



One thing is for sure: from the patient's perspective, the most serious complication of an organ transplant is it not happening at all, says Jaques Pirenne, a transplant surgeon, adding that these operations save lives or at least significantly improve someone's quality of life.

The aim is for more suitable organs to be available. According to H el ene Le Borgne, the person in charge of transplantation matters at the European Commission, this can be achieved through close coordination with more countries, regular communication with citizens, providing information on rights and increasing the rate of transplants from living donors. Transplants also make financial sense: a kidney transplant for someone suffering chronic kidney disease costs half as much as one year of dialysis, while after the operation the state only spends a sixth as much on the patient as before it, without factoring in that the

person in question will live a full life and return to work.

Hungary in Eurotransplant

Hungary joined Eurotransplant in 2013. This means that instead of 10 million Hungarians, 130 million people across the EU can now be considered. There were misgivings about Hungary joining, including concerns that larger countries would "suck Hungary's organ supply dry", and that Hungary would end up exporting organs. Dr R obert Langer, Head of the Budapest Transplantation and Surgery Clinic, says the statistics refute this. While in 2011 a total of 131 transplants from deceased donors were carried out in Hungary, this number rose to 155 in 2013.

As regards combined transplants involving more than one organ, "we have arrived in Europe", as the number of surgical interventions rose from 41 to 75, which is a better rate per capita

than our Western neighbours'. Children, and patients for whom it is harder to find donors due to immunological difficulties, benefit even more than average people from us joining.

Eurotransplant works in the following manner: Hungarian professionals establish whether a patient is suitable for an organ transplant, and if so the person is assigned an ID number and put on the waiting list. The waiting list isn't like a queue at the post office, there isn't an order of precedence. If there is a casualty in any of the participating countries or if a donor becomes available due to a brain haemorrhage, we send the data to Eurotransplant, where a computer programme checks who would be most suitable for the organ(s) on the basis of immunological information, similarity of body size and other data. In this way one donor can save 5-6 patients. In practice, the organ is subsequently sent on the next available flight to person X.Y. However, it is also important that those on the waiting list go for an annual check up and that they keep themselves on the list, points out Dr Éva Toronyi, a lecturer at the Semmelweis University Transplantation and Surgery Clinic. If the organ arrives and only then it is found that the recipient patient is not considered suitable, the organ must be sent without delay to the second person on the waiting list - but this means that valuable time is lost.

Organ donation by living donors

Nowadays it is possible for someone's dependent or blood relative to donate an organ or part of an organ. The most common is a kidney donation, but in Hungary there is also a large number of liver lobe transplants from living donors.

This type of surgery is most successful if the organ is healthy and in good condition and is donated by a relative of the recipient. It is also important that this way the operations are carried out during the planned, morning hours, unlike in cases where the team and the patient must be made available at night if they are suddenly told that someone with a suitable match has died. Moreover, the key to kidney transplants is that the shorter the period during which the patient undergoes dialysis the better the success rate of the organ transfer and the greater the chance of survival. That said, the waiting period can be reduced to a minimum by using an organ from a living donor.

A brand new law permits so-called cross donations in Hungary. This is when someone offers an organ to a loved one but immunologically it is not suitable, and the transplantation clinic helps identify another similar pair which could cross donate with each other.

According to Zsuzsa Szalamanov, the Chair of the Transplant Foundation, in general living donors don't question for a moment that their organ could be used to save someone else. On the contrary, experience shows that it is beneficiaries (recipients) who find it harder to accept that a member of their family should live with only one kidney "because of them". But, she goes on, "patients must accept the donation, because their family needs them and they mustn't die before their time".

What is more, on average living donors live ten years longer than the average population. Part of the reason for this is that they are from a healthy group of the population, otherwise they wouldn't have donated in the first place, and that afterwards they go for regular check ups. It is also interesting that depression among living donors is very rare, and that their self-respect is boosted through believing they actually put something on the (operating) table.

It runs in the family

[PARAGRAPH IN ORANGE:]

Alport Syndrome is, in most cases, a hereditary disease linked to the X chromosome. This means that women may be healthy, be carrying it unaware, or display symptoms. In the case of men, there is a fifty percent chance of a son born to a carrier mother contracting the

disease, but a female sufferer will always pass the illness on to her son. One of the main effects of the syndrome is kidney damage, and it can also affect the hearing and vision.

In the grandparents' generation of the Velkey and Csuti families one of the six siblings died, while the others were either carriers or showed symptoms. In the second generation two cousins, Hilda and Ákos, inherited the disease, and subsequently also Hilda's three sons.

Firstly Simon's kidneys started failing, and when as a teenager he battled with dialysis, his mother's cousin offered him one of his kidneys. Then Ádám started showing symptoms of the disease; miraculously, he very quickly received a suitable cadaver kidney. Lastly, the kidney of Mátyás, the oldest son, also failed and he went to university while performing his own dialysis. One of his mother's cousins also offered him a kidney.

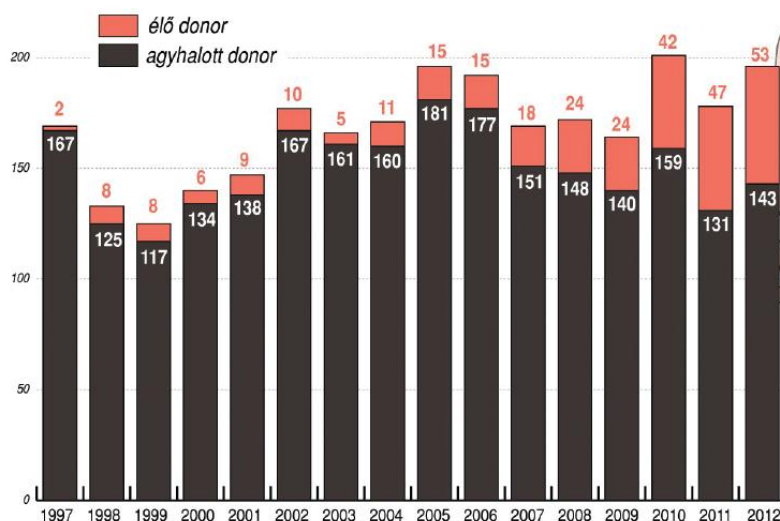
Afterwards, while the mother was managing her sons' recovery, her own kidneys failed and she nursed her family while she herself should have received dialysis. In the end she received a kidney from her uncle. Meanwhile, in the other branch of the family, Ákos fell ill and received a new kidney from a sibling.

As Ákos's sister, Emese Csuti, put it: "We, the second-third generation, decided to save each other". According to Ákos, transplants are often seen as the last resort if dialysis doesn't work. However, a transplant offers the chance of a completely healthy life. Ádám backs this up, saying "I play sport, my life is perfect".

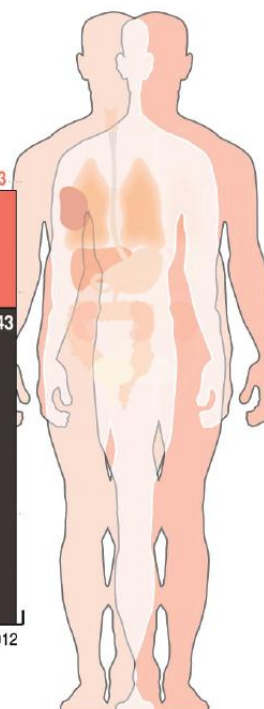
Pál, Hilda's donor, explains his decision by saying "I would have sobbed loudly at the funeral, but this way we're able to continue enjoying each other's company. I have much worse memories about my appendectomy decades ago than about the removal of my kidney."

GRAPH: Number of organ donations in Hungary 1997-2012

Szervdonációk száma Magyarországon 1997-2012



Forrás: Országos Vérellátó Szolgálat Szervkoordinációs Iroda / MTVA Sajtó- és Fotóarchívum / MTI | | | www.mti.hu



Red = living donor

Black = brain-dead donor

Source: Organ Donation Coordination Office of the Hungarian National Blood Transfusion Service / Photo and archive service of the Media Support and Asset

TRANSPLANTS UP CLOSE

[TEXT IN ORANGE BOX:]

BRAIN DEATH: the brain and the brain stem are irrevocably and permanently damaged, and while breathing apparatus keeps the person alive the heart keeps working automatically.

COMA: Not the same as brain death. A coma is the deepest level of mental damage, and can in practice be described as long-term unconsciousness. The person may have their reflexes and may breathe spontaneously, but is not aware of anything.

CADAVER DONOR: a person suitable for providing organ donations, having been declared brain dead following a decision of the appointed committee.

OPTING IN SCHEME: In some European countries an organ can be removed from a person to be used for transplantation only if during their lifetime they declared their wish for this to happen. Campaigns have been carried out in several countries to encourage more people to sign up as organ donors.

OPTING OUT SCHEME: Hungarian law considers that someone would have offered their organs, thus if they are a suitable donor for someone they can 'automatically' be selected after their death, unless while alive they had expressly said they did not want this to happen. (Of course things are not that simple, and obviously the family must also be involved in the decision, but this is on emotional, not legal grounds.)