

Article from the Croatian newspaper *Novi list*

Sunday, 23 October 2011

News

THE GIFT OF LIFE: EUROPEAN DAY FOR ORGAN DONATION AND TRANSPLANTATION

Croatians top of the league for organ donations in Europe

Croatia is the most pleasant surprise in the well-organised network of organ donation and transplantation, having reached the top of the European league, largely thanks to the dedicated work of our transplantation teams

Barbara ČALUŠIĆ

Things suddenly started getting out of hand. Up to her eighteenth birthday it was quite normal for her to stay in hospital several times a month, and then things became even more difficult. But the hardest thing of all was breathing.

When she was at university, not only did she have to make frequent stays in hospital but she also had to take two handfuls of different tablets every day. Actually she ended up having to take tablets all year round: at the last count she can remember she had to take 18 different medicines every day. At first she tried to hide her problem from her colleagues and friends, and even from herself to a certain extent. She gives the example of how she used to conceal from her fellow students the breathing difficulties she experienced after normal gentle walking.

'I used to stop in my tracks and pretend to text someone. Actually I was getting my wind back,' says Emily Thackray, a 27-year-old British blonde who very much loves life and, unlike other people of her age, really knows she does. You can see it in her every gesture and you can hear it in everything she says with a big smile on her face. Today, Emily is the director of a voluntary organisation that helps and supports people who find themselves in a similar predicament. She is happily married and proudly shows photos of her wedding. But six years ago life did not look so rosy.



'It is far easier to give an organ than to accept one', say André Bek and José Rutten | Emily Thackray had a double lung transplant

Stark diagnosis

Back in 2005 she realised that her life was hanging by a thread and that she could only be saved by the selfless love of someone she didn't know. Emily needed new lungs.

'Life gradually became difficult. When I ended up in a wheelchair I was happy because it made me independent again for a short while. I could get about. But not for long. I carried oxygen around with me. The oxygen tank weighed seven kilograms, and it only lasted two hours. If for some reason I used up my week's supply, I had to stay at home next to the oxygen machine, which was terribly noisy. By then hospital had become part of my life, I had spent half of my time there and it had simply become my second home. I was 21 when I was told that I needed a lung transplant.' This is how Emily began the story of her life. When she was still a child she was diagnosed with cystic fibrosis, a hereditary disease which aggressively destroys the internal organs and considerably shortens a person's life. In some cases it affects the digestion system, but in her case it attacked the lungs.

'The news that I needed a transplant was a great shock to me. I thought that only seriously ill people needed transplants, and I didn't think that I was that ill,' says Emily.

But it was much more serious than she thought. Her lung function had fallen to 40 % and the disease was gradually destroying her vital organs: she only had a year left to live. The average wait for a lung transplant in Britain is 18 months. The fight for life had begun, but the outcome was uncertain.

'Waiting for an organ transplant is an experience of a rather particular kind. My suitcase was always ready by the front door because an organ may arrive any day or may never arrive, but you have to be prepared every day just in case it arrives on that particular day. I was so unwell in 2006 that the hospital phoned my family to tell them to come so that we could say our goodbyes. I was alive but I was not living. And then in 2007 the long-awaited call came. The only thing that I managed to say to my family in that turmoil was that I was so happy because the organ was what I had wanted the most in my life. In my case an organ transplant involved a high risk because I was weak and my markers were high. But it was worth taking the risk and spending three months in intensive care. Today everything is different, I can make plans and, what is most important, I can breathe. I can breathe thanks to someone I don't know; the only thing I know about that person and his or her family is that he or she took the right decision, which saved my life in the end,' thinks Emily.



Nearly 60 000 patients throughout Europe are currently waiting for an organ transplant

Anonymous donation

According to the statistics, there were 9 262 organ donors last year in the Member States of the European Union whose organs saved the lives of patients like Emily. Actually, she

was very lucky because 12 patients die every day in the European Union waiting for an organ transplant. This means that, over the whole year, between 4 000 and 5 500 patients lost the battle against their disease after failing to receive a life-saving organ. There are currently almost 60 000 patients on such lists throughout Europe. Judging by the number of organs transplanted, of which there were about 30 000 last year, only half of the patients on the European waiting lists will be included in a transplantation programme. Unlike Emily, who received her organ from someone who had died, one fifth of patients on waiting lists in Europe will receive their organ from a living donor. The organs that are most commonly transplanted from living donors are kidneys, followed by livers. The laws in most European countries require living donors to be family members in order to prevent any organ trafficking. The European champion of organ donations from living donors is the Netherlands, where the rate of transplantation from living donors is 28.5 per million inhabitants. At the same time the liberal Netherlands is one of the rare countries to have extended the possibility of giving an organ to people who are not related in any way, either by birth or relationship, to the person who needs a transplant. The only condition is that the donation must be totally anonymous, which means that the donor cannot decide who is to receive the organ. The number of such donations in the Netherlands remains low but is significant nevertheless: there have been 63 anonymous donations in the past five years.

TOP OF THE LEAGUE

Spain has a rate of 32 post-mortem donors per million inhabitants, and Croatia 30.7

Loving gesture

José Rutten and André Bek are a happy Dutch couple. They are tall and slim and have a smile on their faces; in short, they are typically Dutch. She is head of a company's human resources department and he is a manager. They met at a dance and José says that André just danced into her life, and this shared dance has lasted for 30 years. Dance was the inspiration behind André's book 'Dancing in the sand' in which he writes about the long road to obtaining an organ that saved his life. Along that road, André's body rejected three kidneys that living donors had donated. The fourth finally saved his life. It was José's. Because of kidney disease his body had rejected the kidneys that his father, mother and brother had given him. He now lives with the kidney of his partner, José, who, despite André's resistance and the statutory obstacles, decided to give André quite literally part of herself. It seems that she did not just cure André by donating her organ.

'I also cured myself because I was suffering with him. A transplant simply removes dependence and makes everyone free,' according to José, who says that, in the case of a living donor, 'it is far easier for the donor to give one of his or her organs than it is for the recipient to accept the organ'. André was against the idea of her being the fourth living donor in his life. A person who accepts an organ wonders whether it will ruin the health of the people close to him or her, whether the removal of the organ will be a success and whether his or her body will finally accept the gift of life.

André often wonders how to thank those who are closest to him for the ultimate gesture of love that they made in their efforts to save his life.

'They always answer me, saying simply that I would do the same for them,' André says.

Croatia's pride

According to the Eurobarometer surveys, 55 % of Europeans would do the same after their death, even for someone they did not know. The best example in this area is set by the Swedes, no fewer than 83 % of whom declare that they would agree to donate one of their organs after their death. The figure for Croatians is 53 % (the European average), and the percentage for Spaniards is even slightly higher, since 61 % of them declared their willingness to donate an organ. Moreover, Spain and Croatia are at the top of the league when it comes to actual organ donations. With a rate of 32 post-mortem donors per million inhabitants in Spain and 30.7 in Croatia, these two countries definitely do what they say. Unlike Spain, which has spent many years developing a broad network of public support for the idea of organ donations, starting with the painstaking search for donors, communication with the families of people who have died and a positive media approach, Croatia has managed to reach the top of the European league largely thanks to the dedicated work of transplantation teams in Croatian hospitals.

At the meeting in Brussels organised by the European Commission to mark the European Day for Organ Donation and Transplantation, at which numerous experts in transplantation medicine spoke to some thirty journalists from several Member States of the European Union and *Novi List* as the only representative of Croatia, our country was mentioned as the most pleasant surprise in the well-organised network of organ donation and transplantation.

'You must be very proud to come from Croatia,' Dr Axel Rahmel, the medical director of Eurotransplant, said to us. Given that Emily Thackray and André Bek took part in this meeting, it would be hard not to feel proud after hearing their stories, since the decision to give life to another person is one of the few decisions in someone's life that can never be wrong.