

REPORT [main article]

**Poignant testimonies from donors who have experienced the joy of giving life**

## Europe Ten people die every day awaiting transplants



'I don't feel like a hero. I don't feel like I've done something for which I deserve to be called brave or heroic. But from that day onwards, when I'm asked what organ donation means to me, I answer: It's an act of love.'

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Sofia Ciravegna has a twinkle in her eyes and a smile on her face. Four years ago she made the important decision to donate one of her kidneys in order to save her sick brother's life. Last Tuesday she shared this poignant experience with the European journalists who were taking part in the third workshop on organ donation and transplantation organised in Brussels by the European Commission, and to which *Makedonia on Sunday* (MtK) was invited.

For Sofia, being a living donor was self-evident when she learned that by doing this her brother would not have to be put on a waiting list and that the chances that the graft would take would be better due to high compatibility.

'Of course I was scared, but I wanted to help. My parents couldn't give their kidneys because they were too old. At first my brother refused. He felt guilty. But I had made up my mind. I underwent medical and psychological tests. I am married and I have a daughter. The doctors asked me several times if I had thought about what would happen if one day my child needed something or if my brother rejected the graft. I was undeterred. I knew that I was in good health and that after the kidney donation I would have a normal life' said Sofia.

The transplant took place in July 2008 and Sofia remembers that she was calm and cheerful. Everything went well and the very evening of the surgery she received a text on her mobile. 'Thank you. Now I am living through you', her brother wrote.

'When I met up with him, his eyes were shining with new life. Now he works, plays sport and leads a normal life. I am in good health. The only trace I bear is a scar on my body, which reminds me that everything was worth it', Sofia underlines.

### 'I AM LIVING WITH NEW LUNGS'

At 36, Rafaella Bruno-Pinto, a mother of two children aged 10 and 8, lives a normal life with... donated lungs. Two years ago she underwent a double lung transplant at the Erasme hospital in Brussels. As she explains, her ordeal started in 2008 with a persistent cough, which eventually developed into a dangerous illness that 'ate up' her lungs.

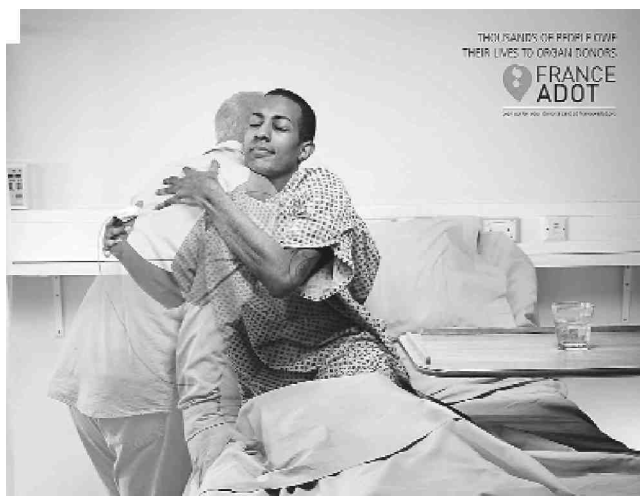
'I couldn't talk without coughing. Just climbing up a few stairs would leave me out of breath. I did a lot of tests until they found what was the matter with me. In March 2010 I climbed up the stairs and suddenly I couldn't breathe and my hands turned blue. I was terrified. I went to the hospital and the doctors said that I needed a transplant. I went home with an oxygen machine. I used to dream about being able to run through the countryside with my children or read to them without being stopped by my cough. But I couldn't do anything', Rafaella explains.

She felt like her time was up. In July 2010 she was bed-ridden and couldn't look after her children or even herself any more.

'I was losing weight. I cut my hair because it was falling out. I was rushed to hospital. I told myself that I would either go home with new lungs or that I wouldn't go home at all. My husband has been my tower of strength from the beginning. A few days later some lungs were found. The transplant lasted 13 hours. Two weeks later I left the hospital. Now I take daily medication to stop my body rejecting the grafts, and other medication to deal with the side-effects. But this is a small price to pay for the new life I have been given. I delight in my children, go skiing and ride a bicycle', says Rafaella.

She acknowledges that 'without the donor, I wouldn't be here. Not a day goes by when I don't think about the donor. I am happy to be alive. I live each day to the full and make every moment count.'

**Waiting list:** 61 500 patients can be saved [Boxed article at bottom of the page]



**Poster urging organ donation. It shows the gratitude felt by patients towards donors.**

At the end of 2011, there were a total of 61 500 patients awaiting transplants in the European Union. Over 42 000 were waiting for a kidney, over 10 000 for a liver, around

4 000 for a heart and around 2 300 for lungs. It is estimated that 5 500 patients died in 2011 in the EU while awaiting a life-saving transplant.

Across Europe in 2011, there were 18 712 kidney transplants (20.6% from living donors), 7 006 liver transplants (3.5% from living donors), 1 980 heart transplants, 1 677 lung transplants and 859 pancreas transplants. A total of 9 604 cadaveric donors were recorded. 'Every day 10 Europeans die awaiting a transplant. A lack of confidence in the system and fear of exploitation of the human body are the main reasons why people are reluctant to become donors', says Stefaan Van der Spiegel, head of the Substances of Human Origin team of the Directorate-General for Health and Consumers of the European Commission. He adds that special emphasis is placed on cooperation between Member States, so that grafts that cannot be used in one country do not go to waste and can be used to save lives in another country.

## **Brave mother**

'My daughter's death was not meaningless'

[Article on the right]



**By donating her daughter's organs, Lia Van Kempen saved the lives of four children and one adult**

In 2000 Lia Van Kempen lost one of her three daughters, who was only 8 at the time. Little Kelly fell down the stairs at home and sustained extremely serious head injuries. The doctors did what they could but the little girl couldn't be saved.

'Prepare yourself for the worst and bid her goodbye. That's what the doctors said to me. The next day she was pronounced brain dead. It was only the machines that were keeping her alive. The doctors asked us to donate her organs. I had already given this some thought the night before. If I had been able to ask her, I'm sure she would have wanted to', said Lia.

The only thing she asked was to be able to hug her daughter one last time, which the doctors let her do. Kelly's death saved the lives of several children and one adult. Her lungs were given to a four-year-old child, one of her kidneys to a two-year-old and the other to an adult, her heart to a three-year-old boy and her liver to a four-year-old girl.

'It is a strange decision. I try and put myself in the shoes of a parent with a sick child whose only chance at life is a transplant. I have never regretted my decision. At least her

death was not meaningless', says Lia. She went on to found an association of relatives of organ donors, the first of its kind, called NAVADO.

## **APPROACHING THE FAMILY**

The transplantation coordinator in Ghent, Belgian Luc Colenbie, talked about the importance of how to approach the family of the potential donor in order to persuade them to donate the organs of their loved one. 'In our first meeting with the donor's family we explain what brain death is. We build up a relationship of trust, give them time to ask questions. We use simple language, in a quiet environment. We listen, offer support and explain that brain death is an irreversible condition. If the family does not understand what brain death is, they cannot agree to organ donation', explains Mr Colenbie.

He adds that transplantation coordinators are continuously trained for the purposes of giving information on organ donation to the families of potential donors and listening to what the family knows about the issue. They always talk respectfully and use the deceased person's first name. They also discuss with the family what the potential donor's views were on organ donation.

'The relationship between the family and the coordinator is a lasting one. The coordinator must be there to support the family psychologically and to give them details of what was done with the organs of their loved one. They also support the family after the transplant by sending them thank you cards and letters from the organ recipients and by sending Christmas cards each year', Mr Colenbie underlined.

The director of the Spanish Transplantation Organisation, Mr Rafael Matesanz, stated that Spain had managed to increase the number of its donors from 14 per million population to 35 per million population. Replying to a question by *Makedonia on Sunday* on organ trafficking, he said that this could not happen between EU Member States because there were stringent checks in place. It was more likely to occur in countries with looser security systems and of course on the internet where transactions are unmonitored.