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EUROPEAN DAY FOR ORGAN DONATION AND TRANSPLANTATION

Transplants: 56 000 people on waiting lists in Europe

Appeal to Member States not to cut health budgets

56 000 people on waiting lists in Europe FROM OUR CORRESPONDENT

BRUSSELS – “Every day in Europe, twelve people die waiting for a transplant. This translates to around 4 000 deaths per year. The level of donations has remained largely static for the past five years, and 56 000 patients are on organ transplant waiting lists.” This snapshot of the situation is provided by [Axel Rahmel](#), medical director of *Eurotransplant International Foundation*, a not-for-profit organisation set up by seven European countries (Austria, Belgium, Croatia, Germany, Luxembourg, the Netherlands and Slovenia) to ensure the best use of donor organs. The 13th European Day for Organ Donation and Transplantation is being celebrated on 22 October in Geneva, to raise Member States’ awareness of the subject and help them to promote a culture of donation. From Brussels, [Paola Testori Coggi](#), the European Commission’s Director-General for Health, is launching an appeal to the Member States not to reduce the resources needed to develop these life-saving treatments in future budgets, despite the general economic crisis. “Apart from the issue of people’s survival, which is clearly of great importance to us, transplants also save money,” said Ms Testori Coggi. “Whether we like it or not, we need to find ways to make our health care more efficient and cost-effective, and organ transplant is therefore one of the areas in which Member States should invest.”

PATCHY PICTURE – The situation is very different in different countries, according to the data presented this week in Brussels on the occasion of a seminar organised by the European Commission’s Directorate-General for Health and Consumers. We asked [Rafael Matesanz](#), who was at the meeting together with [Axel Rahmel](#), to describe the situation. [Matesanz](#) is the director of the National Transplant Organisation (ONT), which in ten years has raised Spain from the lowest ranked country for transplants to become the leading nation. After the ONT was set up, the Iberian country saw donations rise from 550 in 1989 to 1 606 in 2009. “There are big differences between the leading countries, namely Spain, Portugal, France and Italy, and middle-ranked countries, such as Germany and the United Kingdom, and particularly Eastern Europe, which is ranked much lower,” [Matesanz](#) said. “In Spain we have an average of 34 to 35 donors per million inhabitants, while in Romania and Bulgaria there are two or three per million. These are huge differences which are not difficult to understand in a common area like the European Union aims to be”.

CAUSES – It is not easy to understand the reason behind such a pronounced difference. [Matesanz](#)’s theory is that “the main cause is a problem with the general health care system. There are quite pronounced differences between Western Europe and Eastern Europe, meaning that the emerging countries have a very low donation rate. But there is also a North-South divide. In this case, however, the South has the upper hand, because those Mediterranean countries that have adopted a general system of intra-hospital medical coordinators have a higher donation rate. This has been the case in Spain for many years, but now also in Portugal, Croatia, Northern Italy, Belgium and France.”

SPAIN’S WINNING MOVE – The secret of Spain’s success? “It’s not that crucial to invest a lot of money in advertising campaigns to persuade people to donate. What’s more important is to invest in the organisation of the transplant system and in training professionals. In Spain, we

have trained 11 000 doctors and nurses and about 300 transplant coordinators. We carry out training with young intensive care practitioners and first aid professionals. This is because the opinion of the doctors present at the delicate moment of death is decisive as to whether or not donation will take place. We have now also begun training neurologists, because they are responsible for the Stroke Unit. For our part, we have also invested a lot in information in general. We have set up an emergency number which anyone - family, health professionals, journalists too - can call 24 hours a day for news."

THE SITUATION IN ITALY – Around 9 000 patients are on the transplant waiting list in Italy, with a gulf between North and South in terms of the number of donations. "We have to compare ourselves to Europe," said Alessandro Nanni Costa, director of the National Transplant Centre (NTC). We are ranked third of the large countries. Spain is ahead of us, we are quite close to France, and we are ahead of organised health care systems such as Germany's and the UK's. We have a problem which is unique to us at European level, and that is age. Due to the age of Italy's donors today, there are fewer organs. We are already suffering as a result of this. The standards that are applied tend to lead us to make a wider selection, precisely because age is increasing. So in this situation of scarcity of donations and serious economic crisis, our position seems reasonable." To put this into context, according to data from the Council of Europe for 2010, Italy has an average of 21.6 donors per million inhabitants, compared to 23.8 in France, 16.8 in the United Kingdom, and 15.8 in Germany. NTC data up to 30 September of this year show that the system remained essentially stable, but there was no increase. "For 11 years we have experienced growth, mainly thanks to the organisation recommended by the national transplant system," explained Vincenzo Passarelli, president of the Italian Organ Donation Association (AIDO). "This organisational model, which was taken up by the most effective Regions, boosted numbers to such an extent that Tuscany now has an average of over 40 donors per million inhabitants, with Friuli following close behind with 39 donors per million. But other regions, such as Campania and Sicily, struggle to reach 10 donors per million." So where is the fault in this system? Why don't people want to donate? "We trace it back to the organisational system - we've found that where there is a functioning, organised health care system, the donation system functions too." For example, many health workers in many hospitals still do not know that they could draw attention to the presence of a potential tissue donor, according to AIDO. But even transplant coordinators themselves seem ineffectual. In Spain, there are 300 full-time coordinators. In Italy, coordinators are often intensive care doctors who dedicate only part of their working hours to transplants, while continuing to carry out their routine work. "However, in our opinion, their performance in both could suffer," Passarelli warned. Alessandro Nanni Costa, however, invites us to consider what happens in Italy under the current transplant system: "We are the only European country that publishes all data on all transplants on a website. We have clear rules on allocation that are regularly reviewed; good and careful management of waiting lists; the prospect of increasing the number of transplants from living donors and expanding the Pavia centre's initial experiment on stopped hearts; extremely interesting experiments on organ recovery; and also a solid framework with regard to training staff, with limited resources, in agreement with Matesanz's theory that training staff is the most effective measure. All this is clearly indicative of a system."

THE OBSTACLE OF CONSENT – To put the problem of donations into clearer context, it should be recalled that there are two types of informed consent to donate organs: explicit consent, which is the model applied in Italy and seven other European countries, and presumed consent (where consent is considered to be given if the patient has not indicated the contrary), which is applied in the remaining 19 Member States. So far only 1.6 million Italians have registered their consent in the transplant information system. These are the people who have given their consent to AIDO or have joined the donor card scheme, although the latest Eurobarometer survey shows that 59% of Europeans are in favour of donating their organs after death, and 53% are in favour of their relatives donating organs, in spite of the fact that in reality there is always a degree of opposition from the families. "In Spain the level of opposition is under 20%," Nanni Costa explained. This year we are seeing the level decrease from 31.5% to 29%, which in absolute terms is a reduction of about 8 to 9 per cent." In its Resolution of 19 May 2010 on the European Commission's 2009-2015 action plan on organ donation and transplantation, the European

Parliament explicitly confirmed: "Rates of refusal of organ donation vary widely within Europe, and such variability could be explained by the level of training and expertise of professionals in terms of communication and family care, the different legislative approaches to consent to organ donation and their practical implementation, and other important cultural, economic or social factors that influence society's perception of the benefits of donation and transplantation." The focus should be on the family and informing the family, including on the part of the relative who has hopefully declared consent to donate. "Under the law of 1999, the family would have to give evidence if they believed that their relative had refused a donation," said Vincenzo Passarelli, president of AIDO. However, even today, in 78% of cases the family is not the witness but the decision-maker. This means that at the precise moment of death, the family cannot take a decision because they do not know what their relative's view on the matter was. This is why it is essential that individuals talk to their family after having made the declaration, as the "*Parlane*" ["Talk about it"] campaign urges. That way there is also a testimonial. The family's opposition to donation stems precisely from not knowing what the relative's wishes were, or the perception that there was more that could have been done to save their loved one, or because they only become aware of the problem when the coordinator asks them whether or not they agree to donation."