

## **Transplantation**

### **European dimensions and Bulgarian reality**

By Darina Stoeva, in Forum Medicus (25 November 2013)

*At the end of last week there was a donor situation in Bulgaria. The intensive care clinic at Tokuda Hospital provided information (for the first time) about a potential donor — a 49-year old woman from the city of Ruse who had been declared brain-dead and whose family had given its consent to donate her organs. The competent institutions and medical teams responded immediately. Following 8 hours of surgery performed at the Military Medical Academy, the liver was transplanted to a 14-year-old boy in a serious condition, who a few days earlier had been declared an emergency transplant patient. A day later, the kidneys were transplanted to a 32-year-old woman and a 56-year-old man at the Aleksandrovska Hospital...and this was considered to be news.* It should not have been. This is not only because transplants are now an integral part of modern medical therapy anywhere in the world but also because we already know that Bulgaria has everything it needs to develop the science and practice of transplantation. Facilities and legal regulations are in place, as well as qualified medical teams. So why make news out of it? Possibly, because there have only been eight such 'donor situations' this year (up to November). Or because Bulgaria is bottom of the chart for number of organ transplants per capita, as compared with other countries. Another likely reason is that the lack of trust in the healthcare system puts relatives of those who have died off donation. We could add a wide range of factors, from the national mentality to the readiness of intensive care staff to think about transplant donation and to work for its goals. It is easy to say there are no donors. This is true but a lack of organs to transplant is a problem all over the world. It is easy to say there is no

organisation in place. This is not true: the number of successful transplants carried out in Bulgaria (small as it may be) proves the opposite. Words can be played with but they cannot hide the disturbing figures. At the moment, in Bulgaria, 965 people are on the waiting list for a kidney, 50 for a liver, 32 for a heart, and 6 for lungs. These figures explain how far we have to go before transplantation is no longer seen to be news. A conference for journalists organised by the Directorate-General for Health and Consumers (DG SANCO) of the European Commission in October 2013 also addressed the areas of concern and national responses to various aspects of transplantation. The organisers had prepared a busy and varied programme for the conference in Brussels. They reported on 48 projects that the European Union had financed and supported from 2003 in the field of transplantation. Topics discussed in detail included exchange of best practices, transplantation standards, the establishment of registers, and training of professionals. Speakers commented on the three principal sets of directives relating to SOHO (substances of human origin): 1) on Blood: Directive 2002/98/EU setting standards of quality and safety for the collection, testing, processing, storage and distribution of human blood and blood components; Directive 2002/98/EC on setting standards of quality and safety for the collection, testing, processing, storage and distribution of human blood and blood components; 2) on Tissues and Cells: Directive 2004/23/EC on setting standards of quality and safety for the donation, testing, processing, preservation, storage and distribution of human tissues and cells, and 3) on Organs: Directive 2010/45/EU on standards of quality and safety of human organs intended for transplantation. The main principles and requirements laid down in the Directives were presented to journalists (from all the European countries) in a comprehensible manner, through examples of the activities of different institutions, including the European Commission, the Council of Europe, Eurotransplant, etc. The emphasis was on training of both trainers and professionals with regard to the identification of potential donors, effective

collaboration between transplant coordinators and professionals from intensive care units, and making standards compatible. Some conclusions were reached with regard to the following: the key moment: making a potential donor real; the key location: intensive care clinics and units; the key role: a donor transplant coordinator to direct all the processes. Axel Rahmel, the medical director of Eurotransplant used his speech to highlight the figures and one again noted that every day in Europe 10 people die while waiting for an organ transplant (i.e. approximately 4000 a year) while the waiting lists contain about 56 000 people. He called the waiting lists “hidden icebergs” posing a threat to the European public health and explained Eurotransplant's mission – to prevent the loss of any organ, not a single one, regardless of distances. Mr Rahmel responded to the 'Forum Medicus' question concerning relations with Bulgaria by saying that he expected a favourable outcome of the procedure under way that would establish a partnership between Eurotransplant and the Bulgarian Executive Agency for Transplantation.

### **What are the difficulties?**

Many speakers expressed different positions, which could be summarised as follows: rising age at death, frequent infectious or cancerous diseases among donors and increased frequency of diabetes. Last but not least, society needs to be aware of the life expectancy of transplanted patients. The intermingling of medical, ethical, legal and social dimensions in transplant processes give rise to difficulties. “Where the question is of life and death, it is important to improve life”, Mr Tonio Borg, European Commissioner for Health told the journalists. He recommended treating the topic without drama or pathos, noting however that “health is for all and everyone should have access to all technologies in medicine”. One of the most prominent speakers was Luc Colenbie, the transplant coordinator for Ghent, Belgium. He shared his personal experience concerning sensitive communication with the deceased person's relatives, giving

advice about how to talk to them, both specifically and generally, about matters concerning life and death. Dr Colenbie demonstrated the role of public media and the power of making personal stories known to the public in the long process of gaining public trust for organ donation. He played a short movie about a transplanted girl who, leaving the hospital in good health and not knowing the donor, hugged many of the people she met – on the stairs, in the shop, on the playground. A hug can say more than thousand words. Dr Rafael Matesanz, Director of Spain's National Transplantation Organisation, has extraordinary presence due to his broad experience and personal communication skills. He showed examples of publications, radio and TV broadcasts that can enhance or damage public perceptions of organ donation. Dr Matesanz defined communication with the deceased person's relatives as a key moment and talked about the training delivered in Spain on this type of communication, calling transplant coordinators “the right people in the right place”. He also gave some figures: at present there are 35.3 donors for every million people in Spain, although in a national survey 50 % of the population stated that they would be happy to donate their organs. Dr Matesanz talked about Spain's difficult but successful progress in improving transplantation rates (a special interview with Dr Matesanz was published in Forum Medicus No 28/2013). New opportunities for development of transplantation through innovation were also discussed at the conference. Experts talked about the achievements and challenges relating to xenotransplantation, making artificial organs, the likelihood of “maximising” the use of donors, as well as to the expansion of criteria, and finally relating to investment in the development of bioengineering as an untapped reserve in this area. The conference participants will not only remember the technological and organisational aspects of transplantation processes in Europe, but also the exciting and truly moving personal experiences that were shared. A mother told us of the difficult decision to donate the organs of her little girl who had died in an accident. 13 years after this donation, five persons still survive in Austria,

Germany and Belgium. Later on, the mother set up an association for donors' relatives as she believed they also needed communication and mutual support. A beautiful young Italian lady described her battle with pulmonary failure and talked about her experience. Rafaela shared with us that sufferers often have very little information on the probable outcomes; she called the pulmonary transplant waiting list "the dying list". Today Rafaela has a new lung, breaths freely and is a goodwill ambassador explaining the meaning and power of donation. Another amazing story belonged to a young woman living with a kidney donated by her own brother. She explained how a gesture like this could raise the spirits of an entire family and make people better persons.

**On a similar theme, instead of a conclusion, I would like to tell you about my neighbour Nasko who has been living for more than 20 years with a transplanted kidney. He is always in a hurry, carrying a large bag. Whenever we meet, he waves at me and passes by - always smiling. I think that today Nasko's smile, the smile of a 14-year old with a 'new' liver and the smiles of many more people might find their way to a home filled with sorrow in Ruse - and shine their light upon it.**