

In focus: the gift of life

Bulgaria bottom of the league table for organ donations and transplants in Europe

FROM AIDA PANIKYAN

At the end of 2011, 61500 patients were on the waiting lists for organ transplants in the European Union: 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. In 2009, 2 855 EU patients received a kidney or a liver from a living donor. In 2010 the figure was 3 852. Only 10% of people who need a new organ will get one.

I was happy to receive a letter from the European Commission confirming my participation at the forum. It became clear at the opening ceremony in Brussels that 75 journalists from 26 countries had applied for the workshop and 32 had been approved. So, *Duma* had competed with 74 European media! My presentation starts with the words “*Duma* is the longest extant Bulgarian daily”.

The journalists’ workshop on organ donation and transplantation is being held by the European Commission for a third consecutive year, on the eve of 13 October – when the Council of Europe celebrates the European Day for Organ Donation and Transplantation. The idea behind this Day is to promote voluntary organ donation. This year, Hungary hosted the celebrations.

Hearing the European statistics, I’m not so proud. Bulgaria was bottom of the league table for EU organ donation in 2011. Last year’s deceased kidney donation rate in Bulgaria was 0.5 per million inhabitants! This means that the organs of four deceased persons were transplanted to patients. The donation rate in Romania is 3.6 per million, in Turkey – 4.2 per million. Spain remains undoubtedly at the top of the European League, followed last year by Croatia – a country with population of 4.5m which is in the final straight for EU accession. A Croatian TV journalist is proudly announcing that “the Croatian transplant surgeons could provide training to all their colleagues on the Balkans”. I could only praise the professionalism of the Bulgarian transplant surgeons and the traditions of this branch of surgery in Bulgaria. (“So what?”, I ask myself...). How could I admit in front of my colleagues and the representatives

of the European Commission that the lack of trust in our health systems puts our society off donation? In 2009, 68% of the Bulgarians questioned were in favour of donation and 12% against it; in mid 2012, the ratio is 58% and 17% respectively. Back in 2009, 7% of respondents said that they would formally refuse donation, and now the figure is 14%!

The government has really ‘worked hard’ to increase the level of mistrust in the last 3 years: they have called doctors ‘criminals’ and ‘murderers’, changed four ministers and over a dozen deputy ministers, three directors of the NHIF and a similar number from the Agency for Transplantation. Various campaigns are going on under the motto ‘Best medical doctors’, but what’s the use now!

Brief history

In mid-August 2009 the Prime Minister promised that he would find money, even if he had to draw a bank loan, and would guarantee transplants for all Bulgarians on the transplant waiting lists. In the meantime, the head of the Executive Agency for Transplantation (EAT) Prof. H. Koumanov was dismissed for unclear reasons. Several months later a Fund for Transplantations Abroad was established and BGN 5 million allocated by the state. Only a few people could benefit from organ transplants abroad; BGN 4.7 million were restored to the budget. Transplant waiting lists grew longer and before the year ended, the Fund stopped functioning. At the same time – in the spring of 2011 – the Head of EAT, Dr. Teodora Dzhaleva, was dismissed too.

Awareness of the issue comes next in importance to public confidence in the health system. It is also largely dependent on state policy - non-governmental organisations can only provide support and promotional campaigns. Training of healthcare workers and healthcare administration staff, and training of coordinators and media should be part of any consistent state policy. These are some of the small but key factors in improving donations rates in countries like Spain and Belgium – this I gather from the contributions made by Dr Rafael Matesanz, who founded the country’s organ transplantation system and Dr Luc Colenbie, at the seminar on 9 October in Brussels. In Spain, some changes to legislation and the work performed by donor transplant co-ordinators resulted in a 130% increase of donations over a period of 10 years. Matesanz pays serious attention to the media.

Do Bulgarians discuss human organ donation with their family?

Whereas 40% of Europeans talk at home about this issue, only 22% of Bulgarians do so. 28% of Europeans and 15% of Bulgarians are aware of their national legislation in the field of organ donation and transplantation, a European Commission's survey of October 2009 shows.

Has this situation in Bulgaria changed over the last 3 years? What we have known for two years is that 2747 Bulgarians have refused to be donors.

By the end of April 2012, 866 people were waiting for their chance to disconnect from the haemodialysis equipment and live with a new kidney. In August 2012 they already numbered 902 and on 22 October the figure was 919. At the same time, 44 people were waiting for a liver, 30 for a heart and 5 for lungs.

The 'best' year was 2010, with 68 transplants. According to experts, this was due to the massive MH campaign and improved coordination between hospitals. In that year there was even an exchange arrangement in place between Bulgaria and Eurotransplant. However, 'blue' MPs launched a scandal about the alleged illegal export of organs. Another scandal started early in 2012 – Lozenets Hospital was accused by parents and NGOs of carrying out illegal transplants in children, resulting in the death of some of the patients. EAT seemed to find some irregularities, but the hospital rejected the allegations... all of this however undermined public confidence.

The significant increase of funds allocated to hospitals and specialists carrying out transplants did not improve the situation.

Medical establishments receive up to BGN 20 000 per kidney transplant from a living or deceased donor, and BGN 60 000 per heart transplant (20 000 more than last year). Teams carrying out transplants get up to BGN 75 000 for transplanting a part of a liver, regardless of whether the donor is living or deceased.

Treatment of acute rejection of transplants has been introduced. New financing has been made available for some types of operations, for example up to BGN 5000 for a kidney from a living donor, up to BGN 7000 for a liver from a living donor, and BGN 5 000 for an organ transplant from a deceased donor. The rate of organ donation did not increase even after the introduction of legislative amendments which allowed reimbursement of costs incurred by donors for their rehabilitation and temporary incapacity following the operation.

Transplantation is commonly called “gift of life”.

Fear of manipulation of the human body is a dominant reason for not donating one’s organs for many Europeans and Bulgarians alike. We often feel sad and shed some tears when listening to parents who beg for sponsors' money to pay for their child’s live-saving operation. Every one of us has at least once condemned the state for not providing this type of sponsorship. But how many of us would actually donate their kidney to a child they don’t even know?

Much of the debate about transplantation in Europe and worldwide concerns consent for organ donation after death. “In practice, the consent system doesn’t always make that much difference,” says Axel Rahmel, medical director of Eurotransplant. “In every case, there will be a dialogue with the family and their wishes are always respected, even where they conflict with the person’s wishes.”

Most living donors are close relatives or spouses.

Lia Van Kempen started working for the cause of organ donation 12 years ago, when her nine-year-old daughter died. Kelly suffered brain death following an accident. After the doctor asked if she would donate her daughter’s organs, Van Kempen reflected on what Kelly would have wanted. “I was sure she would have said yes herself. I also tried to put myself in the position of sick people and people with a sick child, for whom there is no other option than to get a donor.” Kelly’s organs were donated to help three children and a 43-year-old man.

Hearing the story of Lia Van Kempen, I remembered the Bulgarian parents who 3 years ago had the courage to donate the organs of their six-year-old boy who fell off the Tsarevets fortress. It seemed to me that many Bulgarians would do that if someone asked them in the right way.

EU donation rates - 2011

DECEASED DONATION RATES (per million of population, pmp)			
Maximum	Spain – 35.3	Croatia – 33.6	Belgium – 30.1
Minimum	Bulgaria – 0.5	Romania – 3.6	Cyprus – 5.5

LIVING KIDNEY DONATIONS (pmp)			
Maximum	The Netherlands - 26.3	Sweden - 19.6	Denmark - 17.9
Minimum	Lithuania - 0.9	Poland - 1.0	Bulgaria - 1.2

Source: European Commission

Number of transplants in Bulgaria					
	Kidney transplants from a living donor	Kidney transplants from a deceased donor	Liver transplants from a living donor	Liver transplants from a deceased donor	Heart transplants
2004	21	13	1	0	1
2005	23	10	5	3	2
2006	2	32	1	9	2
2007	16	11	1	6	3
2008	11	6	4	5	3
2009	15	18	4	9	5
2010	12	36	3	13	5
2011	9	8	3	3	2
2012	4	4	1	2	2

Source: EAT website