

## 4<sup>TH</sup> JOURNALIST WORKSHOP ON ORGAN DONATION AND TRANSPLANTATION 7 OCTOBER 2013

### RECENT FACTS & FIGURES

#### PATIENTS ON WAITING LISTS

Totally over **63,800 patients** were placed on **organs' waiting lists** on 31 December 2012 in the European Union (for comparison: 61,500 patients were placed on waiting lists in the EU on 31 December 2011):

- over 50,000 patients on the kidney waiting lists
- over 6,800 on the liver waiting lists
- about 3,400 on the heart waiting lists
- about 2,000 on the lung waiting lists
- about 1,400 patients on the pancreas waiting lists.

The number of **patients who died while placed on waiting lists** in the course of 2012 was estimated to **3,780** for the European Union in 2011 (5,500 patients died while on waiting lists in 2011).

#### Remarks:

**The management of waiting lists** is a national competence (which can partially be delegated to and co-managed with a "European Organ Exchange Organisation" such as Eurotransplant or Scandiatransplant). It includes the definition of criteria to place patients on the list or exclude patients from a waiting list. The lists are generally specific to the types of organ and transplant needed (kidney, liver, lung, heart, pancreas, small bowel, combined transplants...) and might also be specific for children (paediatric transplants).

If no transplant programme is available or if it is only starting in a country, patients might not (yet) be placed on waiting lists, i.e. **the existence or length of waiting lists** also reflects the possibilities to be transplanted, whereas the absence or shortness of a waiting list does not necessarily mean that there is no need for transplants.

#### DONATION RATES IN 2011 AND 2012

[2012 data: provisory data as the 2013 Transplant Newsletter (with 2012 data) was not yet published at the time of finalisation of the present document]

#### DECEASED DONATION RATES (per million of population, pmp; for actual deceased donors)

<b>Maximum</b> in 2011	Spain → 35,3	Croatia → 33,6	Belgium → 30,1
in 2012	→ 35,6	→ 34,8	→ 29,4 Malta → 28,6
<b>Minimum</b> in 2011	Bulgaria → 0,5	Romania → 3,6	Cyprus → 5,5
in 2012	→ 1,2	→ 3,1	→ 4,7

## KIDNEY TRANSPLANTS FROM LIVING DONORS (pmp)

Maximum in 2011	the Netherlands → 26,3	Sweden → 19,6	Denmark → 17,9 Cyprus → 17,3
in 2012	→ 29	Cyprus → 27,9	Sweden → 16,4 United Kingdom → 16,3
	Also:	Iceland → 18,8	Norway → 16,2
Minimum in 2011	Lithuania → 0,9	Poland → 1,0	Bulgaria → 1,2
in 2012	Slovakia → 0,6	Bulgaria → 1,2	Poland → 1,3

(Luxembourg and Slovenia: no kidney transplants from living donors)

## LIVING DONATION REPRESENTS AT EU LEVEL IN TERMS OF TRANSPLANTS:

2,855 transplants (kidney + liver) in 2009  
 3,852 transplants (kidney + liver) in 2010  
 4,100 transplants (kidney + liver) in 2011 (4,196 with Croatia, Iceland, Norway)  
**3,970 transplants (kidney + liver) in 2012** (4,057 transplants with Iceland & Norway)

**20,8 % of all kidney transplants in 2012** (20,6 % in 2011, 19,8 % in 2010, 18,7% in 2009)  
 20,9 % with Iceland and Norway

## IMPROVEMENT OF LIFE AND ADDITIONAL LIFE YEARS

"QUALITY ADJUSTED LIFE YEARS" (QALYS) AND LIFE YEARS	
<b>MORTALITY RATES</b> waiting for a heart, liver or lung	range from 15 to 30%
<b>LIFETIME SURVIVAL RATES</b>	
○ patients undergoing dialysis treatment	10 years
○ kidney transplantation patients	20 years
<b>KIDNEY TRANSPLANTS</b>	93% survival rate in one year following tx
<b>"QUALITY ADJUSTED LIFE YEARS" (QALYS) GAINED:</b>	<b>LIVER</b> transplant: highest QALY gain (11.5)
	<b>HEART</b> transplant: 6.8 QALY gain
	<b>LUNG</b> transplant: 5.2 QALY gain
<b>COST EFFICIENCY - LIVING DONATION</b>	Annual savings in haemodialysis post kidney transplantation => 80,000 euros (French estimate, 2010)

The **quality-adjusted life year (QALY)** is a measure of disease burden, including both the quality and the quantity of life lived. The QALY model requires utility independent, risk neutral and constant proportional tradeoff behaviour. The QALY is based on the number of years of life that would be added by the intervention. Each year in perfect health is assigned the value of 1.0 down to a value of 0.0 for death.

If the extra years would not be lived in full health, for example if the patient would lose a limb, or be blind or have to use a wheelchair, then the extra life-years are given a value between 0 and 1 to account for this.

## RECENT DONATION & TRANSPLANTATION FIGURES FOR THE EUROPEAN UNION

[2012 data: provisory data as the 2013 Transplant Newsletter (with 2012 data) was not yet published at the time of finalisation of the present document] <http://www.ont.es/publicaciones/>

Year	Total number of actual deceased organ donors	Total number of transplants	Number of transplants per organ-type					Small bowel
			Kidney (% living donors)	Liver (% living donors)	Heart	Lung*	Pan-creas	
2009	<b>9152</b>	<b>28860</b>	<b>17886</b> (18,7%)	<b>6687</b> (3,1%)	<b>2090</b>	<b>1418</b>	<b>779</b>	n.a.
2010	<b>9206</b>	<b>29209</b>	<b>18246</b> (19,8%)	<b>6655</b> (3,6%)	<b>1984</b>	<b>1505</b>	<b>769</b>	<b>50</b>
2011	<b>9604</b>	<b>30290</b>	<b>18712</b> (20,6%)	<b>7006</b> (3,5%)	<b>1980</b>	<b>1677</b>	<b>859</b>	<b>56</b>
2012	<b>9534</b>	<b>30731</b>	<b>19084</b> (20,8%)	<b>6968</b> (3,6%)	<b>2004</b>	<b>1810</b>	<b>830</b>	<b>35</b>

\* Heart-lung transplants are counted under lung transplants

- a constant evolution in the number of deceased organ donors
- also a constant progression in the number of living organ donors
- an overall progression in the total annual number of transplants

## TRANSPLANT DONOR COORDINATORS

- The combination of an efficient system for organ donor identification, detection and procurement has been identified as one of the keys to increasing deceased donation. In particular, the presence of a key donation person at hospital level (transplant donor coordinator), whose main responsibility is to develop a proactive donor detection programme, is the most important step towards optimising organ donation and improving donor detection rates.
- The appointment of transplant donor coordinators in Spain increased donation rates from 14 donors pmp in 1989 to 33 to 35 donors pmp in just a few years.
- The Working group on Deceased donation under the EU Action Plan on Organ donation and Transplantation (national experts) has developed and finalised in 2011, for national Competent Authorities and experts in the field, a Manual on how to set up a system for Transplant donor coordination.
- All Member States already employ transplant donor coordinators (see results of the ACTOR study\*, in particular on Priority Action 1 of the EU Action Plan).

\* Study financed under the EU Health Programme on the set-up of organ donation and transplantation in the EU Member States, uptake and impact of the EU Action Plan on Organ Donation and Transplantation (2009-2015):

[http://ec.europa.eu/health/blood\\_tissues\\_organs/docs/organs\\_actor\\_study\\_2013\\_en.pdf](http://ec.europa.eu/health/blood_tissues_organs/docs/organs_actor_study_2013_en.pdf)

TRANSPLANT (TX) DONOR COORDINATORS	
<b>SPANISH REFORMS</b> (including appointment of transplant coordinators)	donation rates increased 130% (10 years)
<b>GREECE</b> (introduction of transplant coordinators)	132% increase in transplant rates (between 2001 and 2005)
<b>ITALIAN REGION OF TUSCANY</b> (introduction of Spanish Model)	doubled donation rate in 1 year

## DONATION AND TRANSPLANTATION NUMBERS PER COUNTRY (2011 DATA)

Tx = transplants; All Transplant rates are indicated per million population (pmp).

COUNTRY	NUMBER OF DECEASED DONORS <sup>1</sup>	DECEASED DONATION RATES pmp	KIDNEY TX FROM DECEASED DONORS pmp	KIDNEY TX FROM LIVING DONORS pmp	LIVER Tx pmp	HEART TX pmp	LUNG Tx pmp
AUSTRIA	205	<b>24,4</b>	<b>42,9</b>	6,5	<b>15,2</b>	<b>6,1</b>	<b>14,3</b>
BELGIUM	331	<b>30,1</b>	<b>43,1</b>	3,6	<b>27,2</b>	<b>6,9</b>	<b>10,1</b>
BULGARIA	4	0,5	1,1	1,2	0,8	0,3	-
CROATIA	148	<b>33,6</b>	<b>51,8</b>	2	<b>28,2</b>	<b>8,6</b>	-
CYPRUS	6	5,5	10,9	<b>17,3</b>	5,5	-	-
CZECH REPUBLIC	185	17,6	<b>30,5</b>	3,8	8,4	<b>6,5</b>	1,7
DENMARK	73	13	24,1	<b>17,9</b>	9,1	<b>5,2</b>	<b>5,4</b>
ESTONIA	22	16,9	<b>30,8</b>	3,1	6,2	-	2,3
FINLAND	93	17,2	17,2	2,4	10,4	3,3	4,3
FRANCE	1630	25	<b>41,1</b>	4,6	<b>17,9</b>	<b>6,3</b>	<b>5</b>
GERMANY	1200	14,7	25,1	9,7	<b>14,7</b>	<b>4,5</b>	4,1
GREECE	79	6,9	12,2	4	3,7	0,5	-
HUNGARY	131	13,1	20,4	4,7	4,4	1,4	-
IRELAND	93	20,7	<b>36,7</b>	6	13,6	1,3	1,8
ITALY	1325	21,8	25,3	3,5	<b>17</b>	<b>4,6</b>	2
LATVIA	40	18,2	<b>33,6</b>	1,4	0,5	1,4	-
LITHUANIA	39	11,8	21,8	0,9	3,6	1,5	0,3
LUXEMBOURG	9	18	-	-	-	-	-
MALTA	12	<b>30</b>	<b>30</b>	<b>15</b>	-	2,5	-
THE NETHERLANDS	227	13,6	25,1	<b>26,3</b>	8,1	2,6	4,1
POLAND	553	14,4	27	1	7,8	2,1	0,4
PORTUGAL	301	<b>28,1</b>	<b>45,1</b>	4,4	<b>20,5</b>	4,3	1,7
ROMANIA	77	3,6	6,7	3,5	3	0,3	-
SLOVAKIA	69	12,5	21,1	2,4	4,5	3,5	-
SLOVENIA	31	15,5	23	-	10	<b>7</b>	-
SPAIN	1667	<b>35,3</b>	<b>46,3</b>	6,6	<b>24,1</b>	<b>5</b>	4,9
SWEDEN	146	15,5	26,7	<b>19,6</b>	<b>16,6</b>	<b>5,5</b>	<b>6,4</b>
UNITED KINGDOM	1056	17	27,7	<b>16,5</b>	12,2	2,4	3,1
ICELAND	2	6,7	-	<b>36,7</b>	-	-	-
NORWAY	127	<b>24,5</b>	<b>45,8</b>	<b>14,6</b>	<b>17,8</b>	<b>6</b>	<b>5,6</b>
TURKEY		4,2	7	<b>32,4</b>	12,1	1,2	0,1

*Highest rates are indicated in bold.*

*This table reflects the numbers of transplants taking place in the country mentioned, including patients transplanted via an official bilateral agreement between two countries. For example, there is a bilateral agreement between Spain and Portugal for lung transplantation: Portuguese patients might be transplanted in Spain with Portuguese or Spanish organs, but as the transplantation takes place in Spain, it is counted in Spain.*

*Pancreas and Small bowel transplantation numbers are available p. 11-12 of the 2012 Transplant Newsletter: [http://www.edqm.eu/medias/fichiers/newsletter\\_transplant\\_vol\\_17\\_no\\_1\\_sept\\_2012.pdf](http://www.edqm.eu/medias/fichiers/newsletter_transplant_vol_17_no_1_sept_2012.pdf)*

<sup>1</sup> Number of actual deceased organ donors (after brain death and after circulatory death)

## DONATION AND TRANSPLANTATION NUMBERS PER COUNTRY (2012 DATA)

Tx = transplants; All Transplant rates are indicated per million population (pmp).

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COUNTRY	NUMBER OF DECEASED DONORS <sup>2</sup>	DECEASED DONATION RATES pmp	KIDNEY TX FROM DECEASED DONORS pmp	KIDNEY TX FROM LIVING DONORS pmp	LIVER TX pmp	HEART TX pmp	LUNG TX pmp
AUSTRIA	198	<b>23,5</b>	<b>42,7</b>	7,5	<b>14,9</b>	<b>7,3</b>	<b>14,7</b>
BELGIUM	326	<b>29,4</b>	<b>43,3</b>	5,1	<b>25,2</b>	<b>6,9</b>	<b>11,6</b>
BULGARIA	9	1,2	0,3	1,2	0,5	0,3	-
CROATIA	153	<b>34,8</b>	<b>50,5</b>	2	<b>29,1</b>	<b>10</b>	-
CYPRUS	4	4,7	7	<b>27,9</b>	-	-	-
CZECH REPUBLIC	216	20,6	<b>34,3</b>	6,8	10,8	<b>6,9</b>	1,9
DENMARK	76	13,6	24,6	<b>13,8</b>	8,6	4,7	<b>5,4</b>
ESTONIA	32	<b>23,9</b>	<b>42,5</b>	1,5	6,7	-	1,5
FINLAND	108	20	34,8	2	9,6	4,3	5
FRANCE	1642	<b>25,1</b>	<b>41,1</b>	5,5	<b>17,8</b>	<b>6,4</b>	<b>5,2</b>
GERMANY	1046	12,8	22,2	9,4	13,4	4,2	4,4
GREECE	77	6,8	11,5	3,6	4,2	1,6	-
HUNGARY	143	14,4	22,5	5,3	4,1	3,3	-
IRELAND	78	17	28,6	7	10,9	2,2	3,1
ITALY	1337	22	26,2	3,2	<b>16,5</b>	3,8	1,9
LATVIA	38	18,6	<b>31,9</b>	2,5	-	0,5	-
LITHUANIA	41	13,6	25,2	4	5	3	0,7
LUXEMBOURG	4	7,7	-	-	-	-	-
MALTA	12	<b>28,6</b>	19	2,4	-	-	-
THE NETHERLANDS	256	15,3	28,5	<b>29</b>	8,7	2,2	4,8
POLAND	352	9,1	28,4	1,3	8,5	2	0,4
PORTUGAL	252	<b>23,9</b>	<b>36,2</b>	4,5	13,3	2,8	1,3
ROMANIA	66	3,1	5,8	2,5	3,5	0,1	-
SLOVAKIA	71	13,1	24,1	0,6	5,4	3,7	-
SLOVENIA	47	22,8	30,1	-	13,1	<b>13,6</b>	-
SPAIN	1643	<b>35,6</b>	<b>47,4</b>	7,8	<b>23,5</b>	<b>5,3</b>	<b>5,2</b>
SWEDEN	143	15,1	25,6	<b>16,4</b>	<b>16,1</b>	<b>5</b>	<b>6,3</b>
UNITED KINGDOM	1164	18,4	29,5	<b>16,3</b>	12,9	2,2	2,9
<b>EUROPEAN UNION</b>	<b>9534</b>	<b>18,8</b>	<b>29,7</b>	<b>7,8</b>	<b>13,7</b>	<b>3,9</b>	<b>3,5</b>
ICELAND	3	9,4	-	<b>18,8</b>	-	-	-
NORWAY	117	<b>23,4</b>	<b>43,7</b>	<b>16,2</b>	<b>20</b>	<b>6,4</b>	<b>5,6</b>

*Highest rates are indicated in bold.*

<sup>2</sup> Number of actual deceased organ donors (after brain death and after circulatory death)

## EUROPEAN ORGAN EXCHANGES ORGANISATIONS

### EUROTRANSPLANT

- 8 EU Member States (Austria, Belgium, Croatia, Germany, Hungary, Luxemburg, the Netherlands, Slovenia)
- Covers a population of almost 135 million people
- 1,601 donor hospitals and 72 transplant centres
- Is responsible for the allocation of donor organs in these countries
- Exists since 1967
- Exchange between countries about 20% of all organs transplanted each year
- In 2012: totally 2106 deceased donors
- In 2012: 7355 organs transplanted (3472 kidneys, 607 hearts, 1689 livers, 1311 lungs, 276 pancreas)
- Only about 2% of organs leave or enter the Eurotransplant area
- Support for deceased donation
- For further information: <http://www.eurotransplant.org>

### SCANDIATRANSPLANT

- 5 countries: 3 EU Member States (Denmark, Finland, Sweden), Iceland and Norway
- Covers a population of about 25 million inhabitants
- 10 hospitals performing organ transplantation
- Exists since 1969
- In 2012: totally 447 deceased donors and 337 living donors
- In 2012: 1808 organs transplanted (1116 kidneys, 353 livers, 126 hearts, 145 lungs, 64 pancreas and 4 small bowel)
- Between 10 % (kidney) and 27% (heart) of organs were exchanged between members
- Support for deceased and living donation
- For further information: <http://www.scandiatriplant.org>

### SOUTHERN ALLIANCE FOR TRANSPLANTATION

- 3 EU Member States (France, Italy, Spain)
- Covers a population of 173 million inhabitants
- Exists since October 2012
- Agreement between countries for patients with specific needs
- For further information: [cnt@iss.it](mailto:cnt@iss.it)  
[http://ec.europa.eu/health/blood\\_tissues\\_organs/docs/art\\_spain2\\_2012\\_en.pdf](http://ec.europa.eu/health/blood_tissues_organs/docs/art_spain2_2012_en.pdf)  
[http://ec.europa.eu/health/blood\\_tissues\\_organs/docs/art\\_spain1\\_2012\\_en.pdf](http://ec.europa.eu/health/blood_tissues_organs/docs/art_spain1_2012_en.pdf)

## EXAMPLES OF BILATERAL AGREEMENTS ON ORGAN EXCHANGES

### ITALY AND MALTA

- 2008-2010 => 20 organs (kidneys, hearts, livers) from Malta were transplanted in Italy

### SPAIN AND PORTUGAL

- 2009 => 41 organs offered to Spain from Portugal

The **EU-funded project FOEDUS** (Facilitating exchange of organs donated in EU Member States, 2013-2016) will also support Member States willing to exchange organs and to engage in bilateral or multilateral agreements:

<http://ec.europa.eu/eahc/news/news232.html>

[http://ec.europa.eu/eahc/documents/health/conference\\_27-28\\_06\\_2013/FOEDUS -  
\\_Facilitating\\_exchange\\_of\\_organs\\_donated\\_in\\_EU\\_member\\_states.pdf](http://ec.europa.eu/eahc/documents/health/conference_27-28_06_2013/FOEDUS_-_Facilitating_exchange_of_organs_donated_in_EU_member_states.pdf)