

Journalist Workshop on Organ donation and transplantation Recent Facts & Figures

26 November 2014 – Brussels

Facts and figures presented here refer to: - Patients on **waiting lists** (page 1),

- **Donation** (Europe, 2013 situation, over time, comparing deceased/living donation, globally; pages 2 & 3)
- **Transplantation** (Europe, 2013 situation per type of organ, globally; pages 4 to 7)
- **Policies** (transplant donor coordination, improvement of life, organ exchange, pages 8 & 9)

Figures presented here are extracted from the Council of Europe/ONT annual Transplant Newsletters and from publicly available websites (Eurotransplant, Scandiatransplant, EU-funded projects etc. See also "Useful links").

PATIENTS ON WAITING LISTS

Total numbers of patients on waiting lists reflect an impressive reality, even if they cover data from various transplant systems with different national policies and as well as evolving dynamics (see remarks below) and therefore **only represent the tip of the iceberg**.

A total of over **63,000 patients** were officially placed on **organs' waiting lists on 31 December 2013** in the European Union, i.e. for 508 million inhabitants (for comparison: respectively 63,800 patients and 61,500 patients were placed on waiting lists in the EU on 31 December 2012 and 2011).

If patients from Iceland, Norway and Turkey are added: **86,000 patients** were on the waiting lists (for a total population of 588 million inhabitants).

Approximately, on 31 December 2013:

European Union:	(with Iceland, Norway and Turkey)
• 50,000 patients were placed on the <u>kidney</u> waiting lists,	(70,000 patients)
• 6,700 on the <u>liver</u> waiting lists	(8,500 patients)
• 3,450 on the <u>heart</u> waiting lists	(3,850 patients)
• 2,100 on the <u>lung</u> waiting lists	(2,200 patients)
• 1,300 on the <u>pancreas</u> waiting lists	(1,600 patients)
• 70 patients on the <u>small bowel</u> waiting lists	(70 patients)

It is estimated that **4,100 patients died while officially placed on these waiting lists** in the course of 2013 in the 28 Member States of the **European Union** (respectively 3,780 and 5,500 patients died while on waiting lists in 2012 and 2011). If patients from Iceland, Norway and Turkey are included, it can be estimated that **6,000 patients** died while placed on the waiting lists in 2013.

Remarks: The **management of waiting lists** is a national competence (which can partially be delegated by Member States to and/or co-managed with a "European Organ Exchange Organisation" such as Eurotransplant or Scandiatransplant). The **definition of criteria** to in-/exclude patients on/from waiting lists is also a national competence. These criteria are specific for each type of organ needed (different lists for kidneys, hearts, lung, multiple organs etc.) and often also for the different type of recipients (children / adult). For a good match between the donor organ and possible recipients, these criteria are largely medical (blood group, HLA typing, health status of potential recipients etc.). But they also need to take into account some logistical aspects (such as distance/time for transport) which are often decided upon at national or regional level.

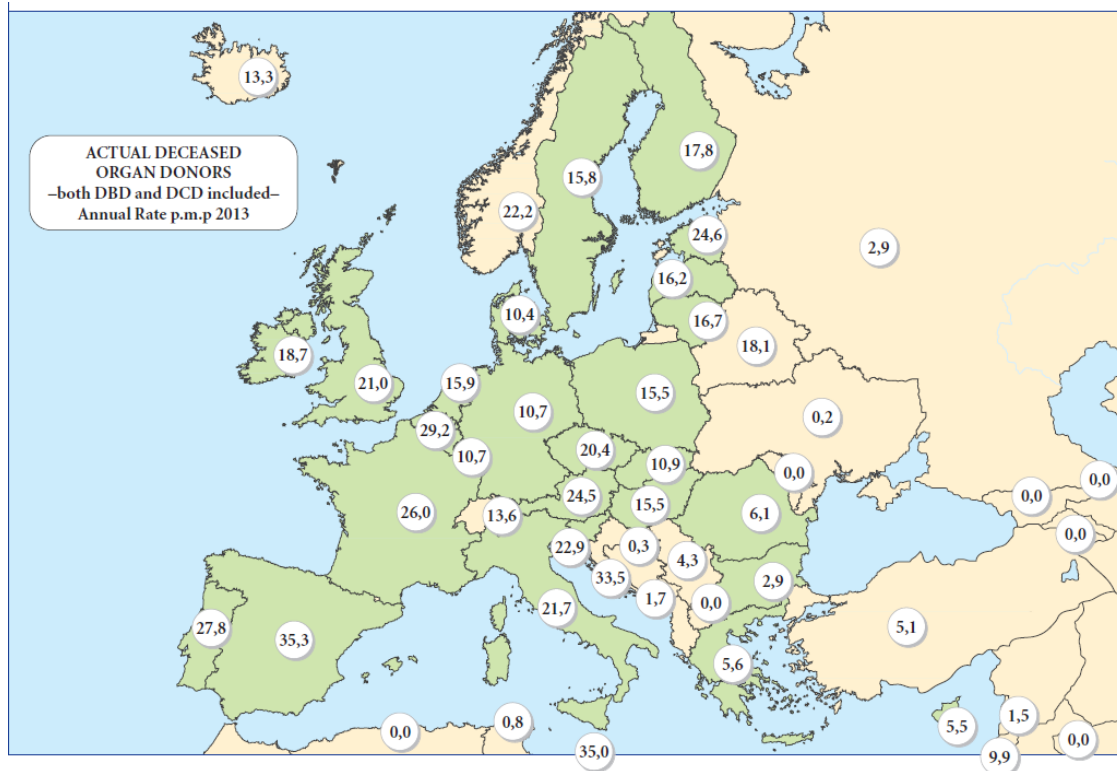
If no transplant programme is available or if it is only starting in a country, patients might not (yet) be placed on waiting lists, i.e. **the existence or length of waiting lists** also reflects the possibilities to be transplanted, whereas the absence or shortness of a waiting list does not necessarily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

The decision to include patients on a waiting list is a collective decision taken by the medical team following the patient. Patients who might need a transplant are not necessarily all, and always, listed on transplant waiting lists: depending on their health status

they can for example be de-listed if they have a temporary infection, if their health status improves or if another therapy or option becomes available (assisted device for heart transplant, living donation for kidney transplant etc.).

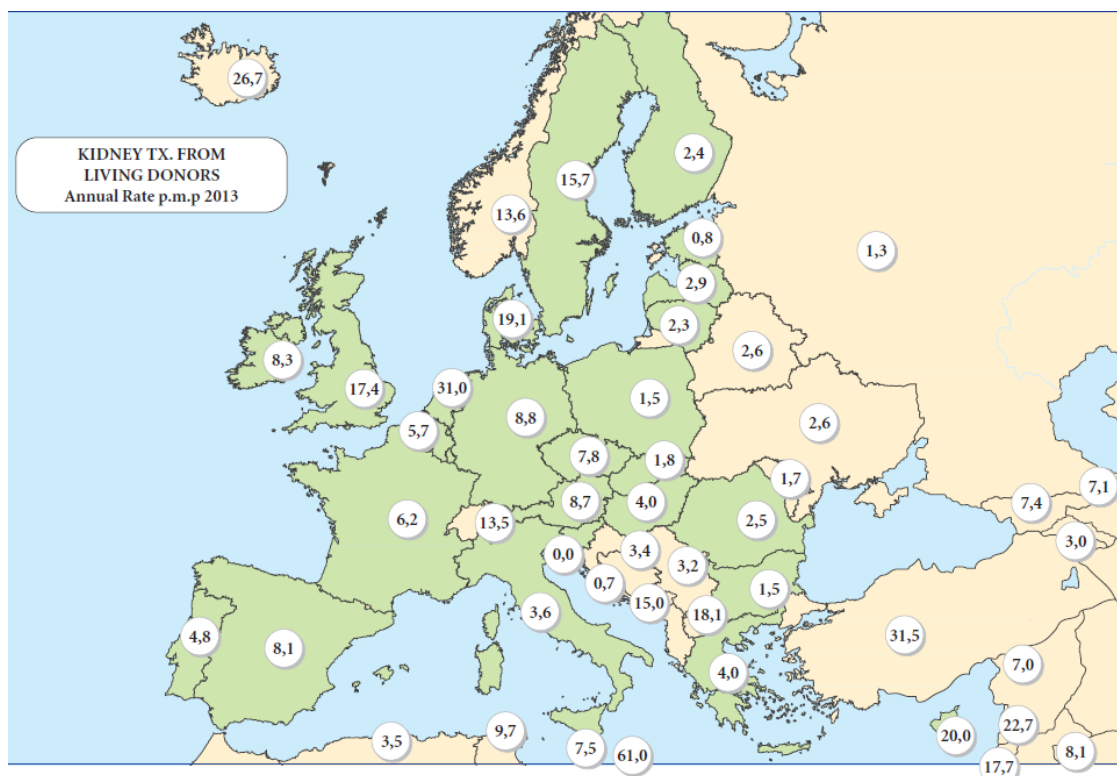
EUROPEAN DONATION RATES FOR 2013

Deceased donation rates per million population Source: 2014 Transplant Newsletter (2013 data)



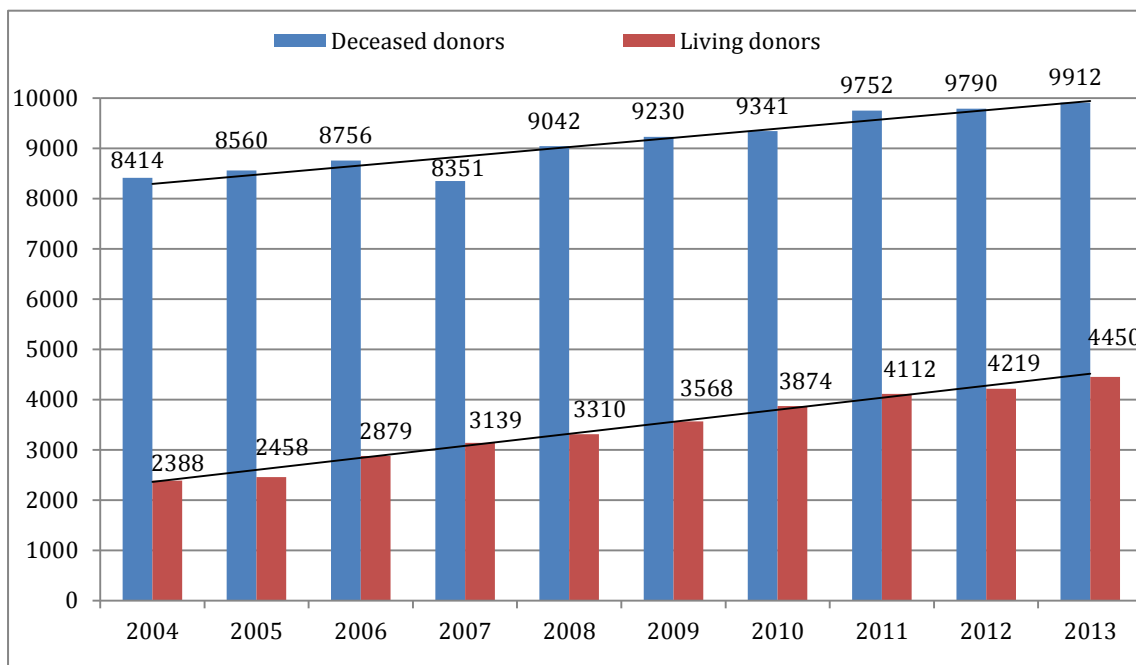
Living donation rates per million population (kidney transplants from living donors)

Source: 2014 Transplant Newsletter (2013 data)



DONATION FIGURES OVER 10 YEARS FOR THE EUROPEAN UNION

Organ transplants from deceased and living donors in the EU, from 2004 to 2013 (All 28 EU Member States in 2013 are captured in this graph, even if they joined the EU after 2004. Source: Annual Transplant Newsletters 2005 to 2014)



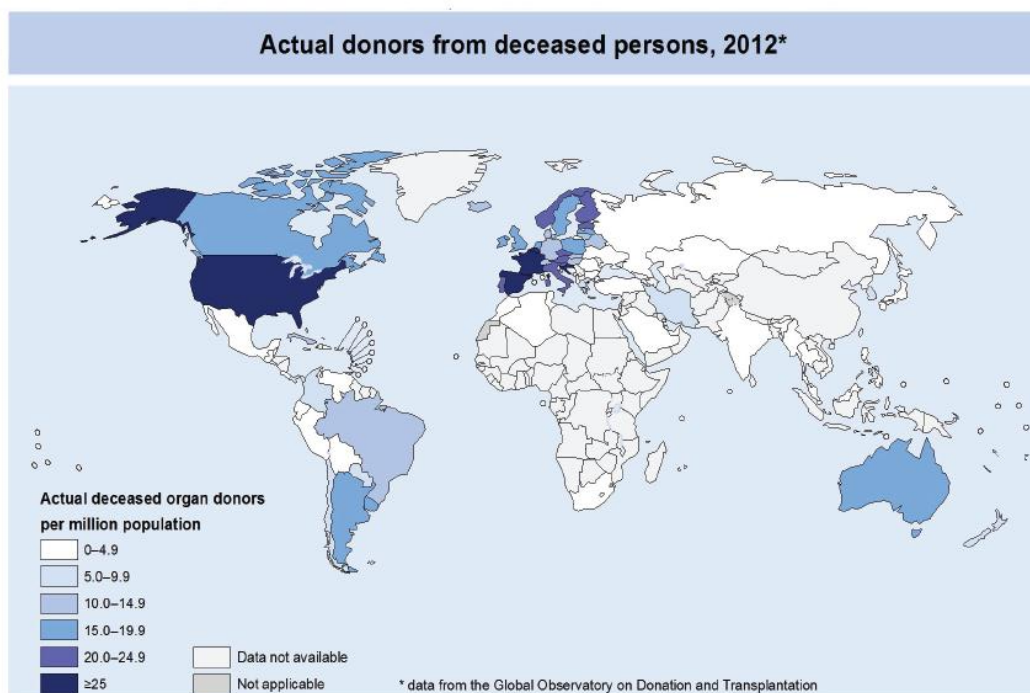
increase in deceased donation + **18 %**

increase in living donation + **86 %**

→ total increase in donation: + **33 %**

ORGAN DONATION GLOBALLY

Source: Global Observatory on Donation & Transplantation (WHO/ONT); Courtesy: B. Dominguez-Gil, ONT

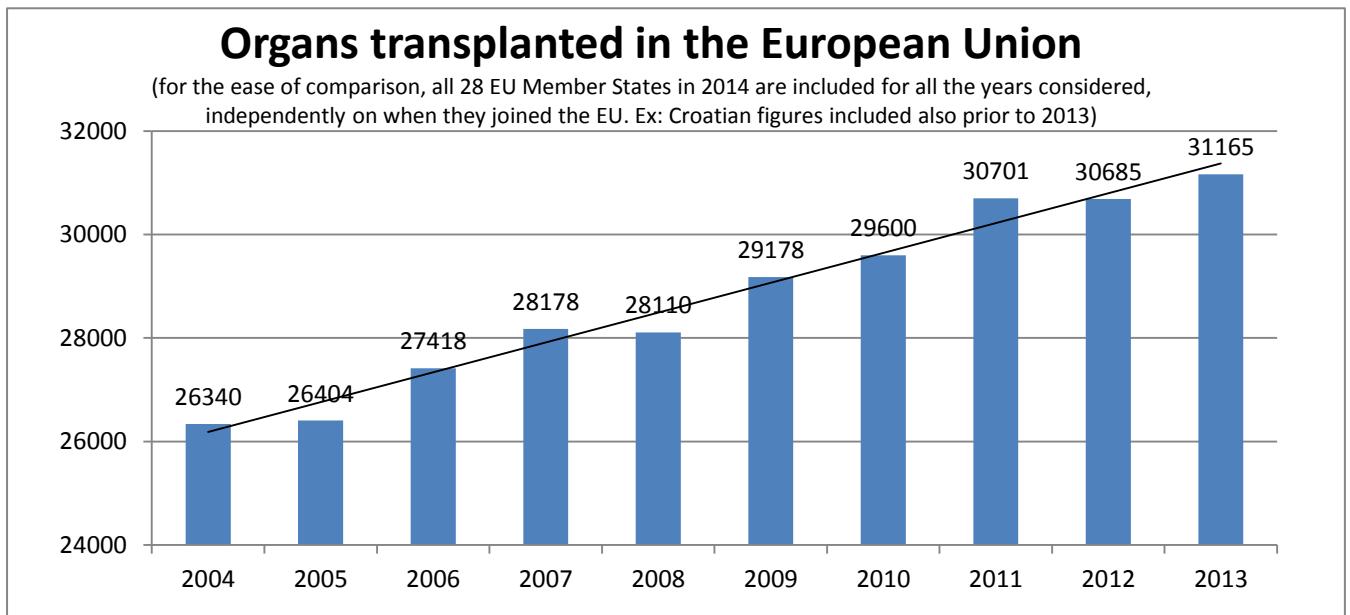


The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

Data Source: Global Observatory on Donation & Transplantation. Map Production: Health Statistics and Information Systems (HSI), World Health Organization

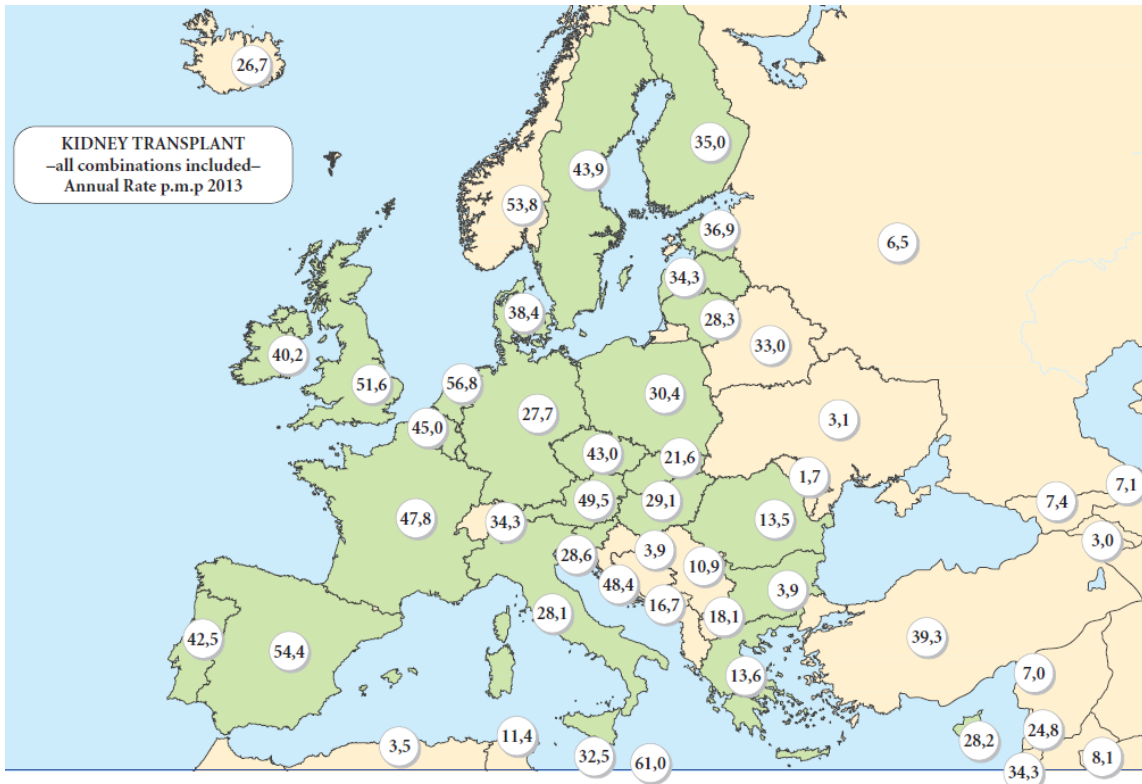
World Health Organization
© WHO 2013. All rights reserved.

TRANSPLANTATION FIGURES FOR THE EUROPEAN UNION FROM 2004 TO 2013

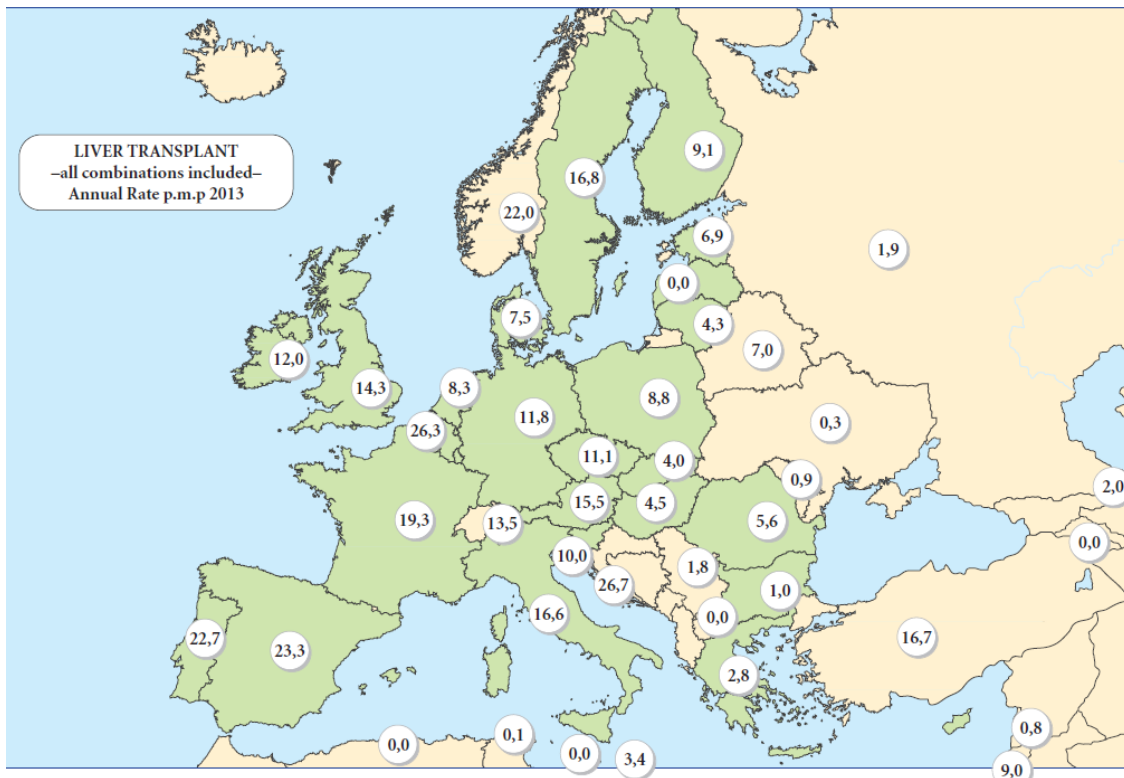


EUROPEAN TRANSPLANTATION FIGURES FOR 2013

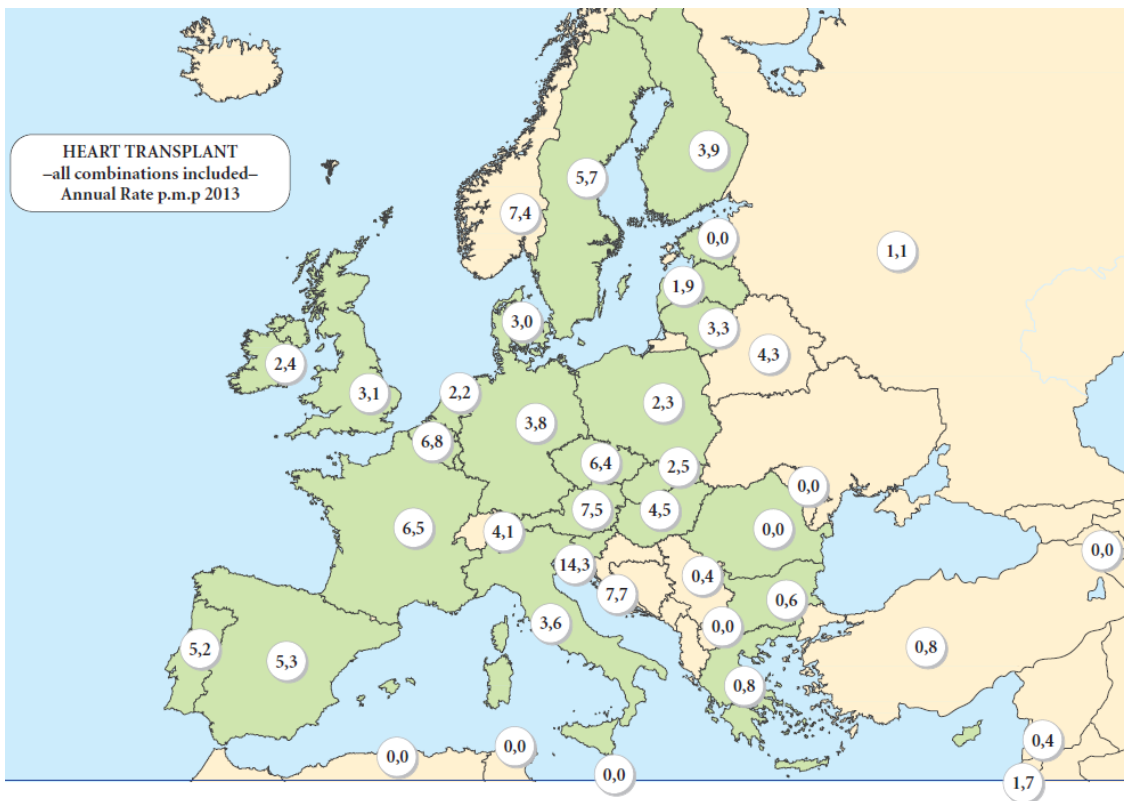
Kidney transplants per million population Source: 2014 Transplant Newsletter (2013 data)



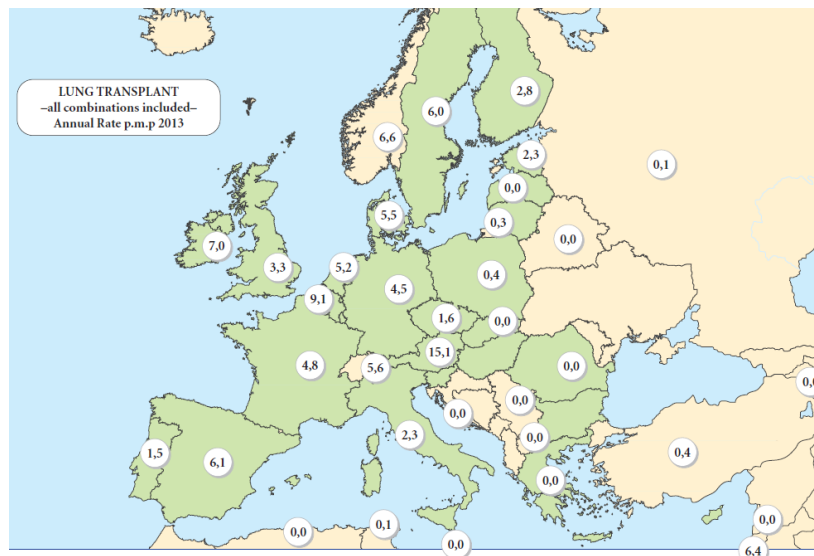
Liver transplants per million population Source: 2014 Transplant Newsletter (2013 data)



Heart transplants per million population Source: 2014 Transplant Newsletter (2013 data)

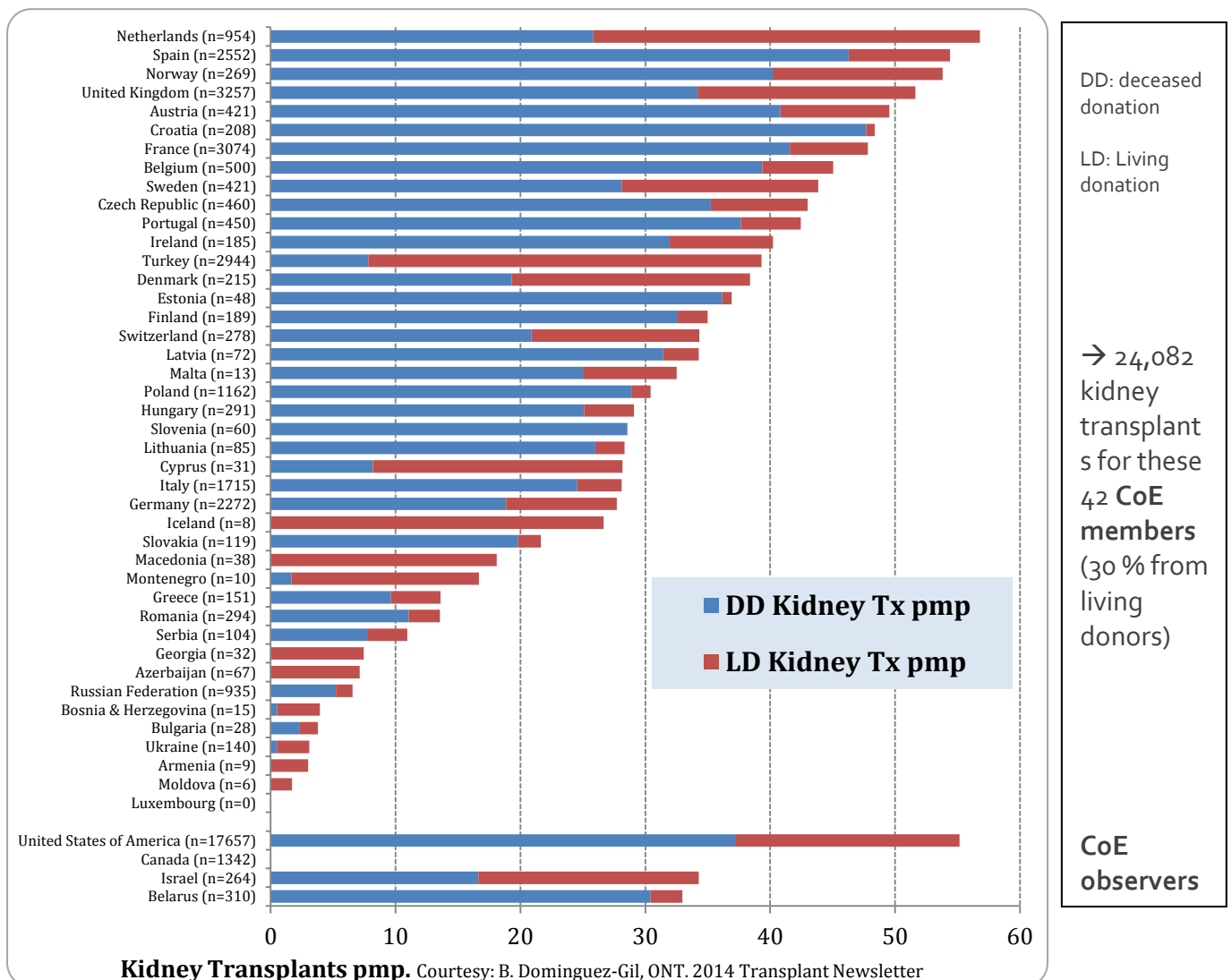


Lung transplants per million population Source: 2014 Transplant Newsletter (2013 data)



BEYOND THE EUROPEAN UNION: COUNCIL OF EUROPE COUNTRIES

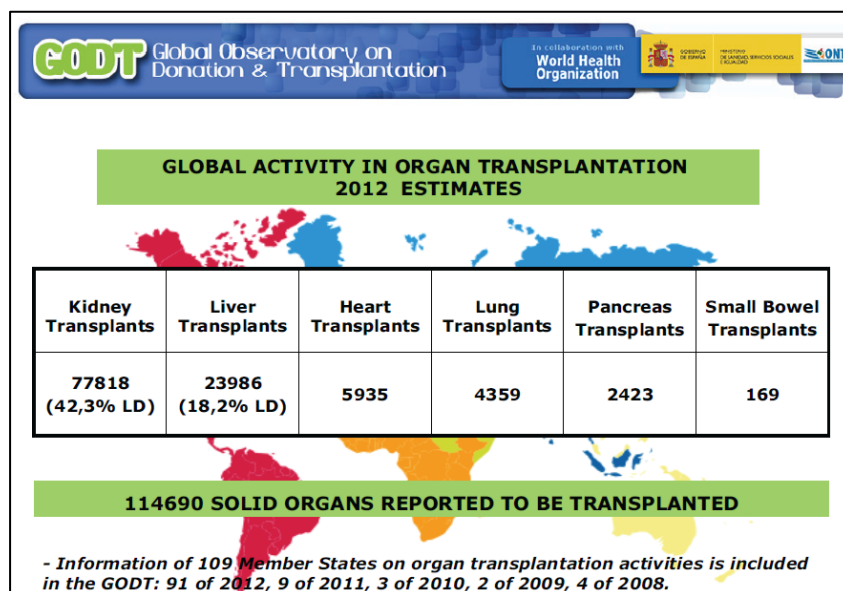
2013 kidney transplants per million population, Council of Europe members & observers



ORGAN TRANSPLANTATION GLOBALLY

Global activity in organ transplantation

Source: 2014 Transplant Newsletter, Global Observatory on Donation & Transplantation



European activities compared to global activity in organ transplantation

Source: 2013 and 2014 Transplant Newsletters, Global Observatory on Donation & Transplantation

2012 transplants	Kidney	Liver	Heart	Lung	Pancreas	Small bowel	Organs transplanted
Global activity (% living donation)	77818 (42,3 %)	23986 (18,2 %)	5935	4359	2423	169	114690
EU (with Croatia) (% living donation)	19085 (20,8 %)	6973 (3,7 %)	2004	1756	833	34	30685
% of global activity	24,5 %	29,1 %	33,8 %	40,3 %	34,4 %	20,1 %	<u>26,8 %</u>
EU incl. HR + Iceland, Norway, Turkey (% LD)	22295 (32,2 %)	8074 (16,8 %)	2099	1809	867	39	35183
% of global activity	28,7 %	33,7 %	35,4 %	41,5 %	35,8 %	23,1 %	<u>30,7 %</u>

- more than 25 % of transplants worldwide took place in the European Union in 2012
 - 24,5 % of kidney transplants worldwide took place in the EU in 2012
 - 34 % of heart transplants worldwide took place in the EU in 2012
 - 40 % of lung transplants worldwide took place in the EU in 2012
- one third of transplants worldwide took place in Europe in 2012
- the rate of kidney transplants from living donors worldwide (42%) is **twice higher** than the rate for the European Union (21%) (for Europe: about 33 % due to high rates of living donation in Turkey)

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 been developed and finalised in 2011, for national Competent Authorities and experts in the field, a Manual on how to set up and further develop a system for Transplant donor coordination.

All EU 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_organ/docs/organs_actor_study_2013_en.pdf

Transplant (tx) Donor Coordinators	
Spanish reforms including appointment of transplant coordinators	donation rates increased 130% (10 years)
Greece introduction of transplant coordinators	132% increase in transplant rates (between 2001 and 2005)
Italian region of Tuscany introduction of Spanish Model	doubled donation rate in 1 year
Romania including appointment of transplant coordinators	doubled the deceased donation rate between 2011 and 2013

IMPROVEMENT OF LIFE AND ADDITIONAL LIFE YEARS

"Quality Adjusted Life Years" (QALYs) and Life years

mortality rates waiting for a heart, liver or lung	range from 15 to 30%
lifetime survival rates	
o patients undergoing dialysis treatment	10 years
o kidney transplantation patients	20 years
kidney transplants	93% survival rate in one year following tx
"Quality Adjusted Life Years" (QALYs) gained	liver transplant: highest QALY gain (11.5)
	heart transplant: 6.8 QALY gain
	lung transplant: 5.2 QALY gain
cost efficiency – kidney transplants from living donation	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 trade-off 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.

EUROPEAN ORGAN EXCHANGE 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 2013: totally 1975 deceased donors
- In 2013: 6236 organs transplanted (3183 kidneys, 589 hearts, 1562 livers, 688 lungs, 214 pancreas)
- About 2% of organs leave or enter the Eurotransplant area
- Support for deceased donation and since recently also for living donation (for Belgium in particular)
- For further information: <http://www.eurotransplant.org> (also statistics)

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 2013: totally 421 actual deceased donors and 352 living donors
- In 2013: 1820 organs transplanted (1103 kidneys, 362 livers, 130 hearts, 137 lungs, 87 pancreas, 1 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.scandiatransplant.org> (also statistics)

South Alliance for Transplants (SAT)

- Founded by France, Italy and Spain. Now 5 partner countries: 4 EU Member States (France, Italy, Portugal, Spain) plus Switzerland and 1 observer: Czech Republic
- Exists since October 2012
- Governed through a rotational biennial presidency (France chairs for 2014-2016)
- Covers a population of almost 202 million inhabitants
- A formal trans-national alliance among south-west European countries to strengthen and implement the cooperation in the field of organs, tissues and cells donation and transplantation
- Exchange of organs for paediatric and adult patients in the absence of a national recipient, and sharing organ requests for urgent paediatric patients
- Hosts an international paired exchange living kidney programme among its members
- 380 organ transplant programmes (145 kidney, 76 liver, 66 heart, 35 lung, 45 pancreas and 13 small bowel)
- In 2013: 5274 deceased organ donors (26.2 pmp) representing more than 50% of total EU organ donors; 14573 organs transplanted (8529 kidneys, 3816 livers, 1061 hearts, 830 lungs, 325 pancreas and 12 small bowels), representing 45.1% of total transplanted patients in EU
- For further information: sat.cnt@iss.it Links: <http://trapianti.net/sat/>
<http://www.agence-biomedecine.fr/Collaborations-with-international>

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) supports Member States willing to exchange organs and to engage in bilateral or multilateral agreements: