



# HORIZONTAL WORK PACKAGES

<b>1</b>	Coordination
<b>2</b>	Dissemination
<b>3</b>	Evaluation



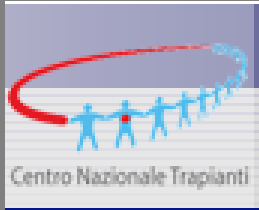
Steering C

- **WP1 - Coordination:** To manage the project and to make sure that it is implemented as planned. Leader: Organización Nacional de Trasplantes, Spain.



- **WP2 - Dissemination:** To ensure that the results and deliverables of the project are made available in the most appropriate manner to the relevant stakeholders. Leader: ISS-Centro Nazionale Trapianti, Italy.

- **WP3 - Evaluation:** To verify that the project is implemented as planned, reaches its objectives and is sustainable and with a potential high impact. Leader: Organización Nacional de Trasplantes, Spain.





# HORIZONTAL WORK PACKAGES

## 1 Coordination

1. To improve the information systems of European Union Member States on living organ donation, particularly through the provision of recommendations for national Living Donor Registries and through setting down a model for supranational data sharing in this field.

## CORE WORK PACKAGES

### 4 Living donor registries



### 5 ICU and DTC collaboration

### 6 Twinning on organ donation and Transplantation



Steering Committee



# Moving Boundaries — The Nightingale Twins and Transplantation Science

Stefan G. Tullius, M.D., Ph.D., Julia A. Rudolf, B.A., and Sayeed K. Malek, M.D.



Johanna Rempel and Lana Blatz sat on either side of Dr. Joseph Murray in the reception room of the Transplant Surgery Division at Brigham and Women's Hospital in May morning in 2011. The

Whether 12-year-old Lana should be asked to donate a kidney to her sister was a delicate question. Lana recalls accompanying her mother to a doctor's appointment and being asked to

work as bookkeepers. Johanna married in 1966, and although her doctors weren't sure how pregnancy and childbirth would affect the transplanted kidney, she had three children after un-

**THE NIGHTINGALE TWINS:  
LIVING KIDNEY DONATION AT 12 YEARS EN 1960.  
BOTH PERFECTLY WELL 54 YEARS LATER**

**JOSEPH MURRAY  
FIRST FUNCTIONING  
KIDNEY GRAFT  
BOSTON - 1955**



Johanna Nightingale with a Doll from President-Elect John F. Kennedy in 1960 (Left), and Johanna (Nightingale) Rempel and Lana (Nightingale) Blatz in 2011 (Right).

# THE FIRST LIVING DONOR "REGISTRY" IN THE WORLD

Richard Herrick ✓ <i>46-2800</i>	12/23/54	Ronald Herrick <i>1.D</i>
Louis Heilman ✓ <i>6J104</i>	2/9/56	Jesse Heilman <i>1.D.</i>
Edith Helm ✓ <i>6J743</i>	5/24/56	Wanda Foster <i>1.D.</i>
Leon Masden ✓ <i>9K904</i>	6/20/57	Leonard Masden <i>1.D</i>
Dolores Huskey ✓ <i>5L253</i>	9/1/57	Doris Huskey <i>1.D</i>
Jimmy Foster ✓ <i>3K793</i>	11/25/57	Jerry Foster <i>1.D.</i>
Robert McDuffie ✓ <i>5L352</i>	1/29/58	Ronald McDuffie <i>1.D</i>
James Ray ✓ <i>3M714</i>	6/13/58	Henry Ray <i>1.D.</i>
Robert Levin ✓ <i>1-39-38</i>	12/4/58	Norman Levin <i>1.D.</i>
Jim Henry Coxey ✓ <i>3N442</i>	3/12/59	Jimmie L. Coxey <i>1.D.</i>
Harold Rosecrans ✓ <i>3-06-29</i>	4/30/59	Howard Rosecrans <i>1.D.</i>
Charlene Hamilton ✓	10/9/59	Charlotte Hamilton <i>1.D.</i>
Johanna Nightingale ✓ <i>0-00-44</i>	12/28/60	Lana Nightingale <i>1.D.</i>
Joseph Skorec ✓ <i>0-15-74</i>	5/9/61	John Skorec <i>1.D.</i>
Robert Wilson ✓ <i>1-02-19</i>	8/15/61	Ralph Wilson <i>1.D.</i>
Gary Tompkins ✓ <i>0-32-14</i>	10/18/61	Larry Tompkins <i>1.D.</i>
Joan Alonge ✓ <i>1-13-05</i>	1/29/62	Joyce Alonge <i>1.D.</i>
Madeleine deVilliers ✓ <i>1-00-09</i>	8/30/62	Charlotte Bousquet <i>1.D.</i>
Florence Lebens ✓ <i>1-41-81</i>	10/1/62	Freda Walton <i>1.D.</i>

**PETER BENT BRIGHAM HOSPITAL – BOSTON:  
TWIN DONORS TRANSPLANTS DURING 50' & 60'**





GOBIERNO DE ESPAÑA

MINISTERIO DE SANIDAD, SERVICIOS SOCIALES E IGUALDAD



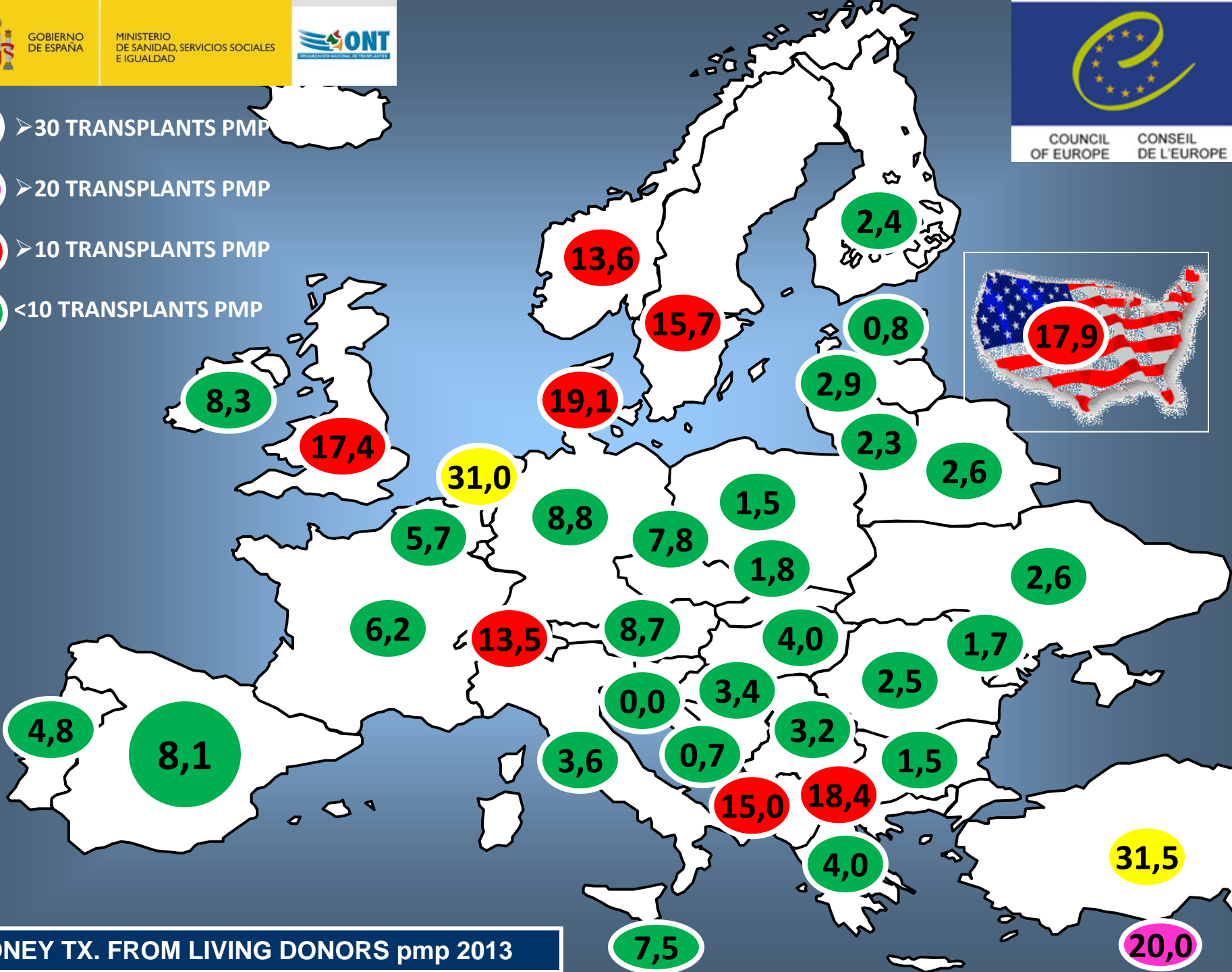
COUNCIL OF EUROPE / CONSEIL DE L'EUROPE

> 30 TRANSPLANTS PMP

> 20 TRANSPLANTS PMP

> 10 TRANSPLANTS PMP

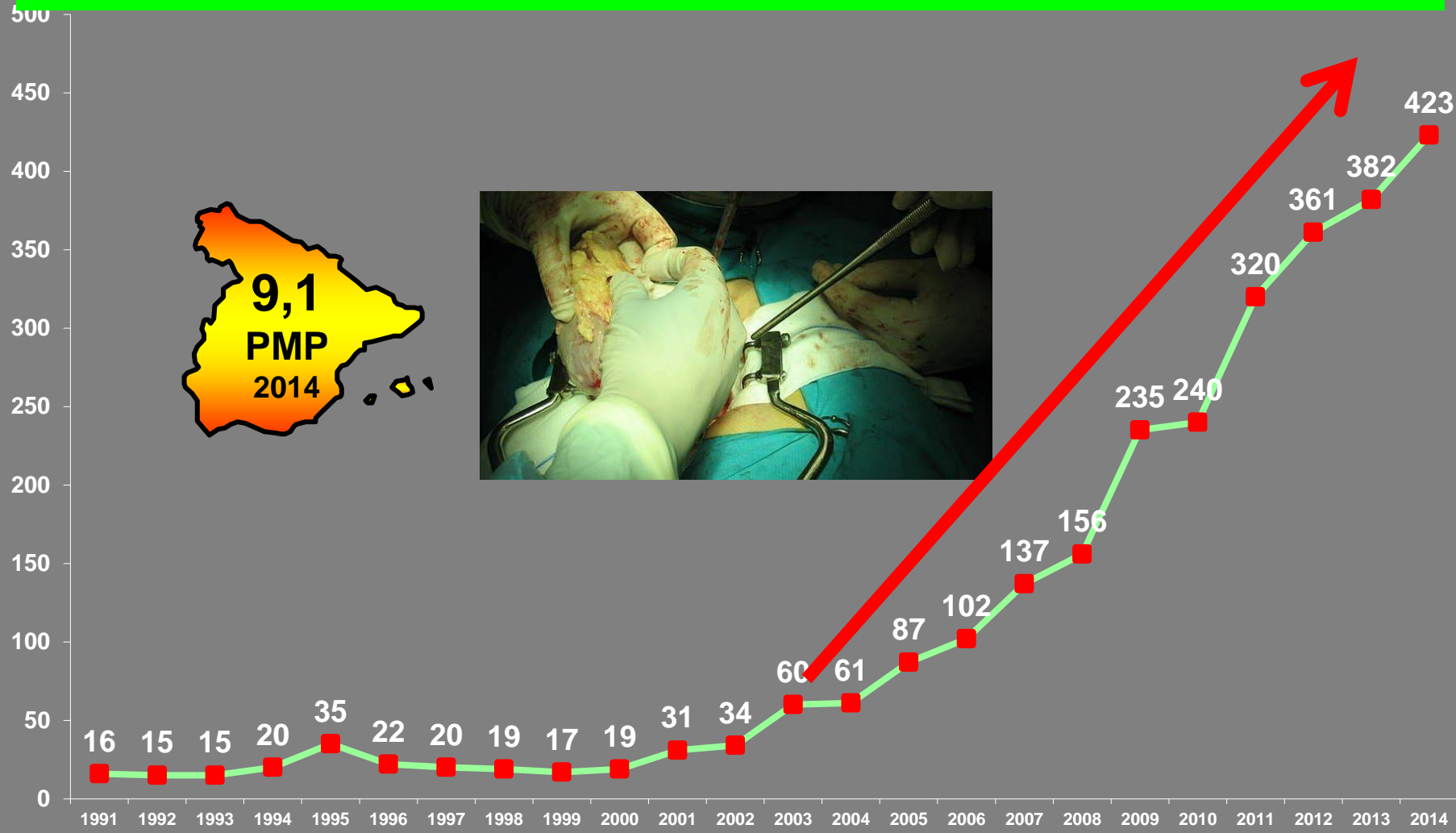
< 10 TRANSPLANTS PMP



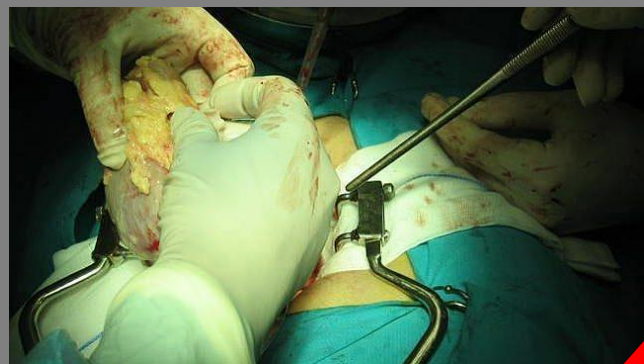
KIDNEY TX. FROM LIVING DONORS pmp 2013

# LIVING RENAL TRANSPLANTS IN SPAIN

## CLEAR INCREASES OF LIVING RENAL DONATION IN SOUTHERN EUROPE



**9,1**  
**PMP**  
**2014**



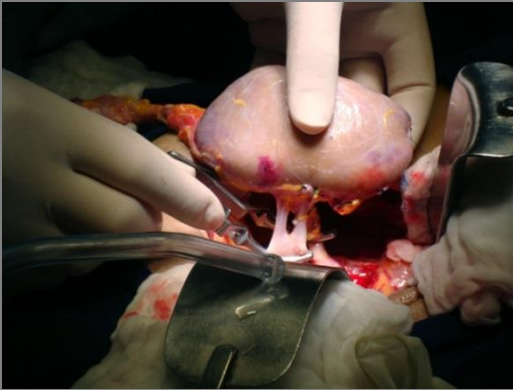
## 15 COUNTRIES ANALYZED THE SITUATION AND ESTABLISHED THE BASIS OF THE EUROPEAN RoR

Eventually a model for sharing data internationally on the outcome of living organ donors was developed. The model builds on the concept of a European registry of living donor registries (RoR), this means the merging of data from existing national registries. An analysis was performed on the legal constraints and the governing, operational and technical requirements of such a RoR were defined.



### Requirements for Registry of Registries:

- ACCORD items and ACCORD definitions
- Relational database
- Web based application
- Approachable by common internet surfing programs
- Official language: English
- Direct data entry possibility
- File upload possibility (from national databases)
- Data download possibility
- Standard report function



## PILOT PERIOD:

- 9 COUNTRIES
  - 4 COUNTRIES WITH PREVIOUS REGISTRY
  - 5 WITHOUT PREVIOUS REGISTRY
- 2909 LIVING KIDNEY DONORS
- YEARS 2010-2011

The pilot confirmed the viability of drafted recommendations and the feasibility of proposed model.



Most importantly, the basis had been established for successful international data sharing on the outcome of living organ donors. Lessons learnt from the pilot helped the consortium to improve a model that will be especially **helpful for countries that do not have any register** in place yet!







# HORIZONTAL WORK PACKAGES

**1** Coordination

**2.** To facilitate the cooperation between two professional groups, critical care professionals and donor transplant coordinators, in order to optimize the realization of the process of donation after death.

## CORE WORK PACKAGES

**4** Living donor registries

**5** ICU and DTC collaboration

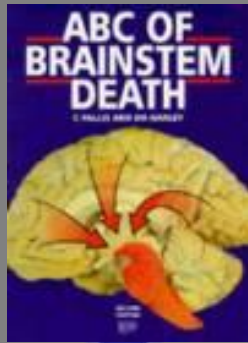
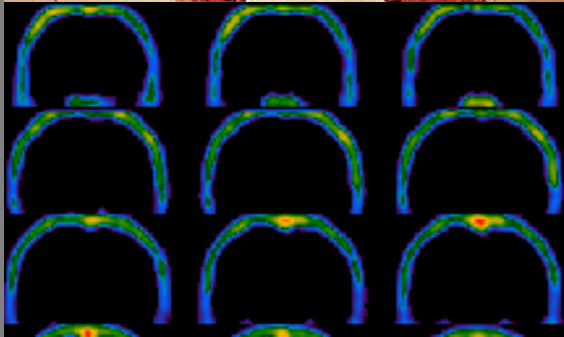
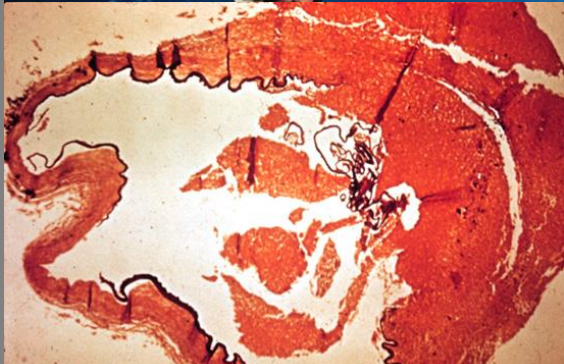


**6** Twinning on organ donation and Transplantation



Steering Committee





**PROGRESSIVE DECREASE OF BRAIN DEATHS**



**ORGAN DONATION FOR TRANSPLANTATION**

**MOST OF CAUSES OF BRAIN DEATHS AND THEREFORE OF ORGAN DONATION ARE PROGRESSIVELY DECREASING IN MOST DEVELOPED COUNTRIES**

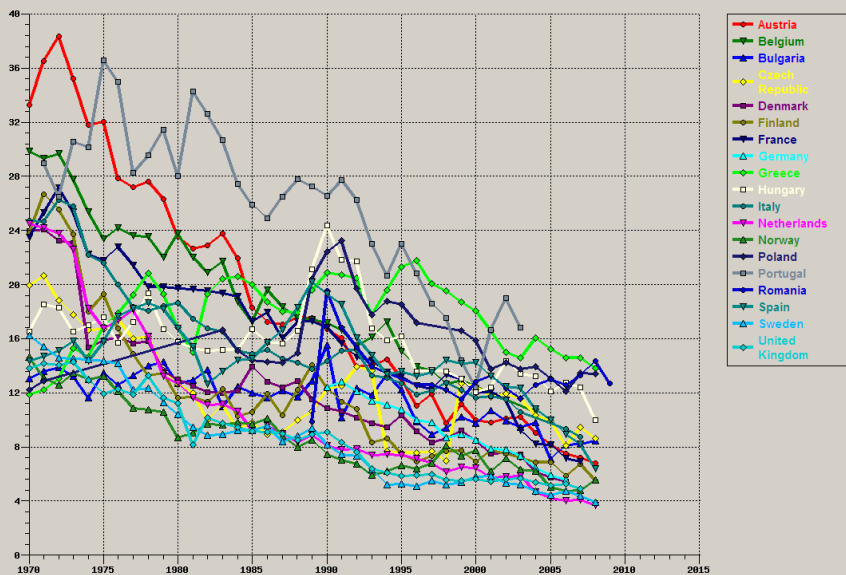


# DECREASE OF MORTALITY RELEVANT FOR ORGAN DONATION IN MOST OF THE COUNTRIES OF THE EUROPEAN UNION



## ROAD TRAFFIC ACCIDENTS / 100,000 hab.

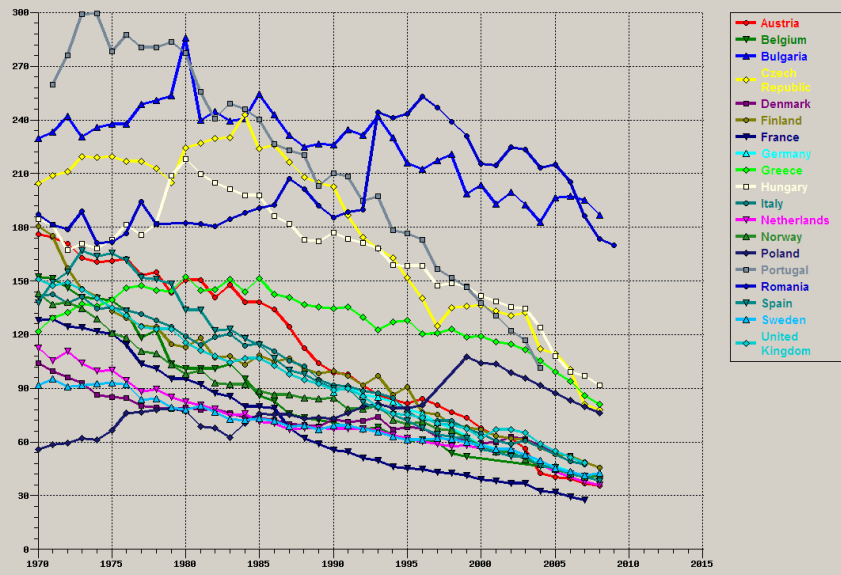
SDR, motor vehicle traffic accidents, all ages per 100000



Source: WHO/Europe, European HFA Database, July 2010

## CEREBROVASCULAR DISEASE / 100,000 hab.

SDR, cerebrovascular diseases, all ages per 100000



Source: WHO/Europe, European HFA Database, July 2010



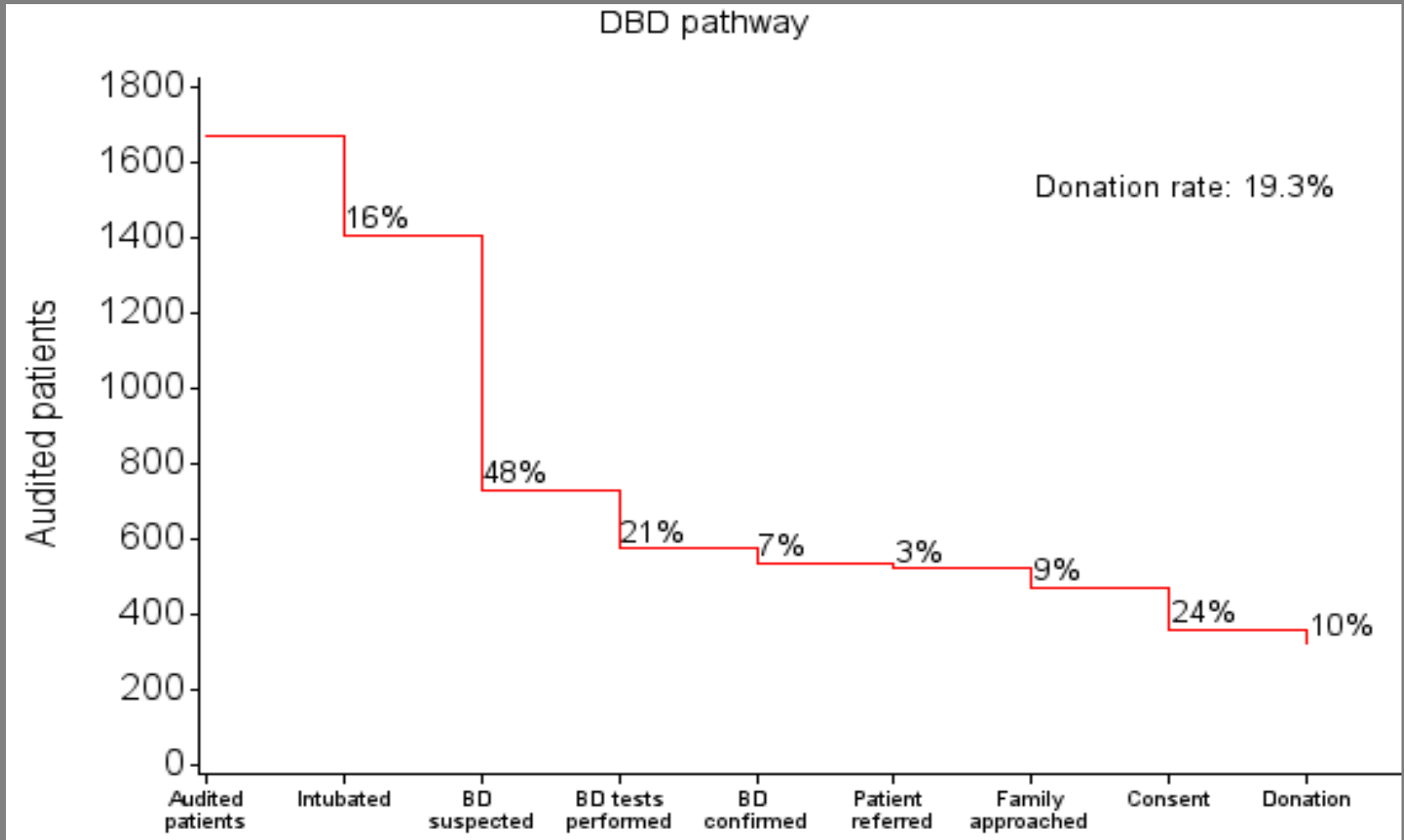
- Which are the pathways of care applied to patients who die as a result of a devastating brain injury in Europe?
- Do they differ from country to country?
- To which extent do these pathways impact on organ donation?  
*ACCORD has worked to answer these questions.*



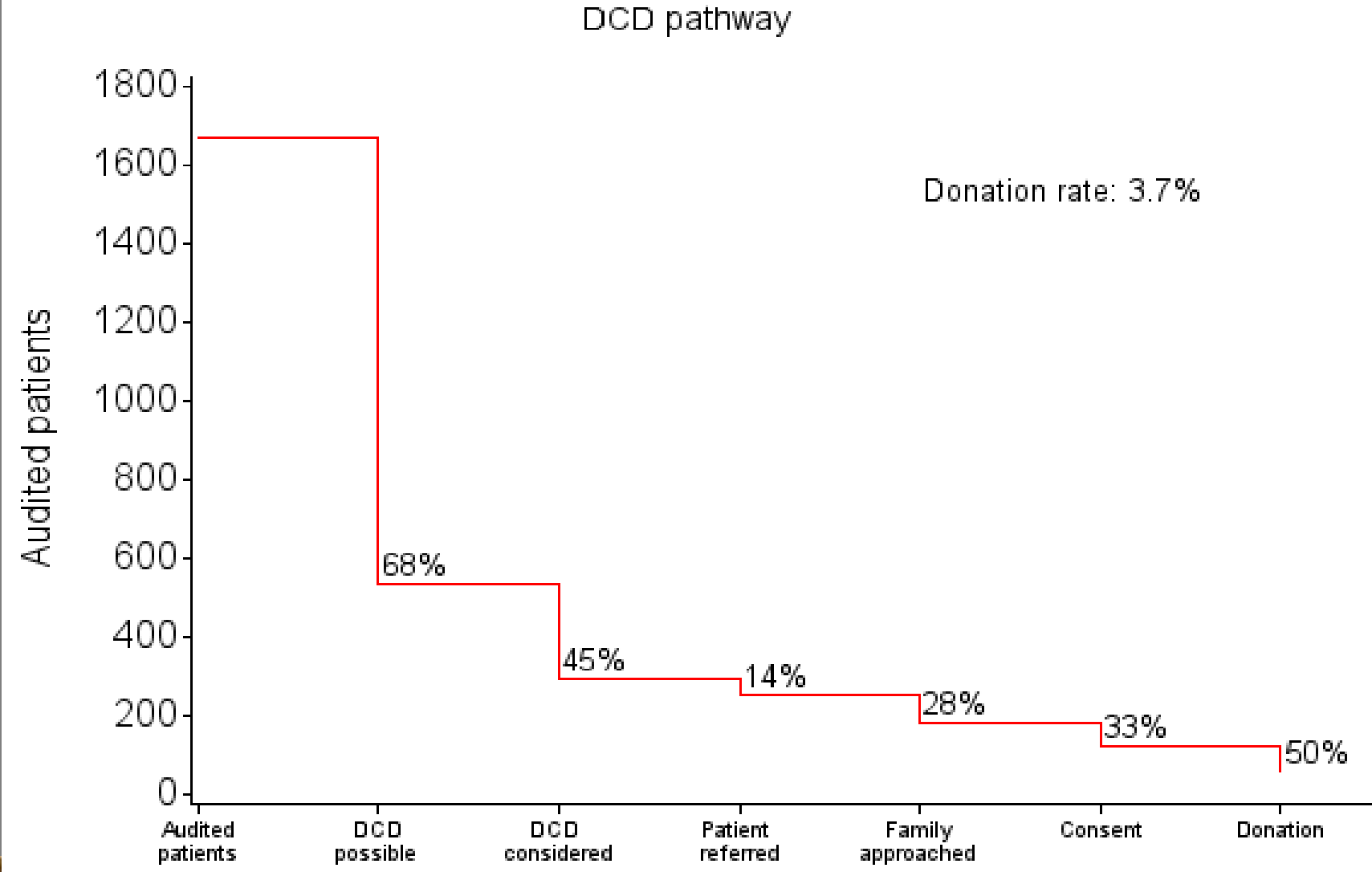
- An in-site review of **variations in end-of-life care pathways** for patients dying as a result of a devastating brain injury was performed at a sample of hospitals from participating MS.
- The **67 participating hospitals from 15 MS** (**Croatia, Estonia, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Netherlands, Portugal, Slovenia, Spain and UK**) were required to identify and collect data on a maximum of 50 consecutive patients who had died of pathologies known to be common causes of brain death.
- **They supplied data for a total of 1,670 patients, by replying to specifically-developed questionnaires.**
- The analysis of these data allowed to draw a clear picture of differences in end-of-life care across countries and, very importantly, to identify barriers to donation in the European setting



# The pathway of donation after brain death in Europe.

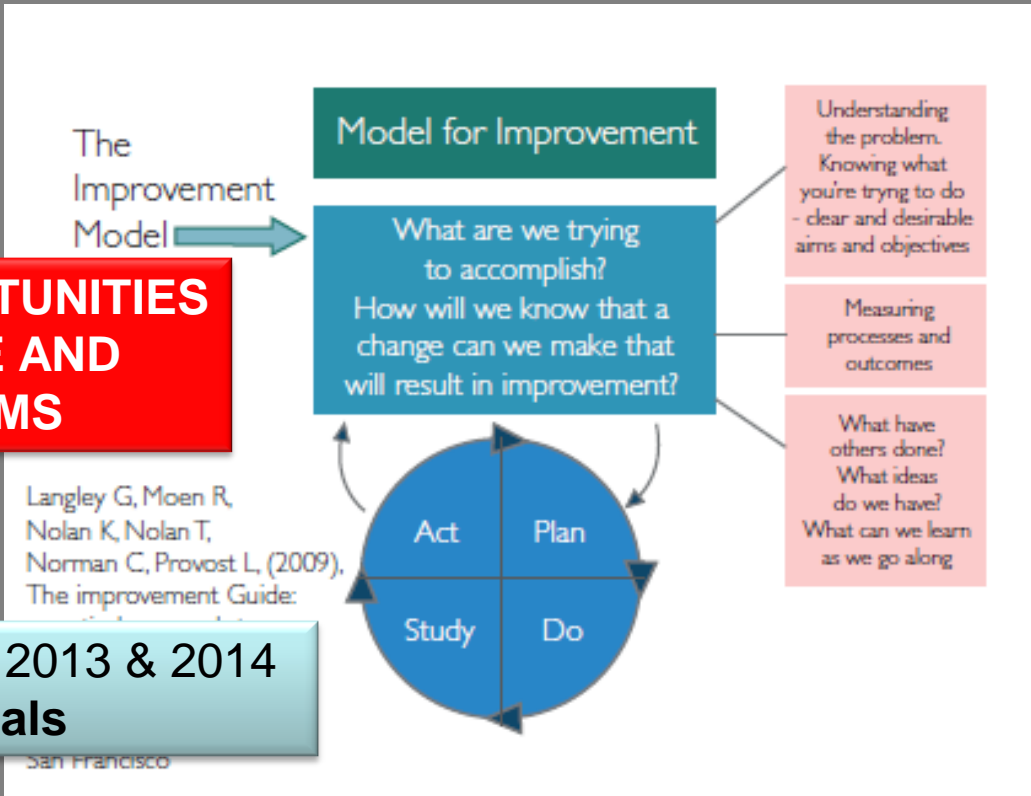


# The pathway of donation after circulatory death in Europe.



**A tested methodology (Plan, Do, Study, Act) for prompting needed changes in participating hospitals** was presented and taught at dedicated training sessions. This included **training experts** that could support clinicians to identify achievable interventions and use the methodology to change.

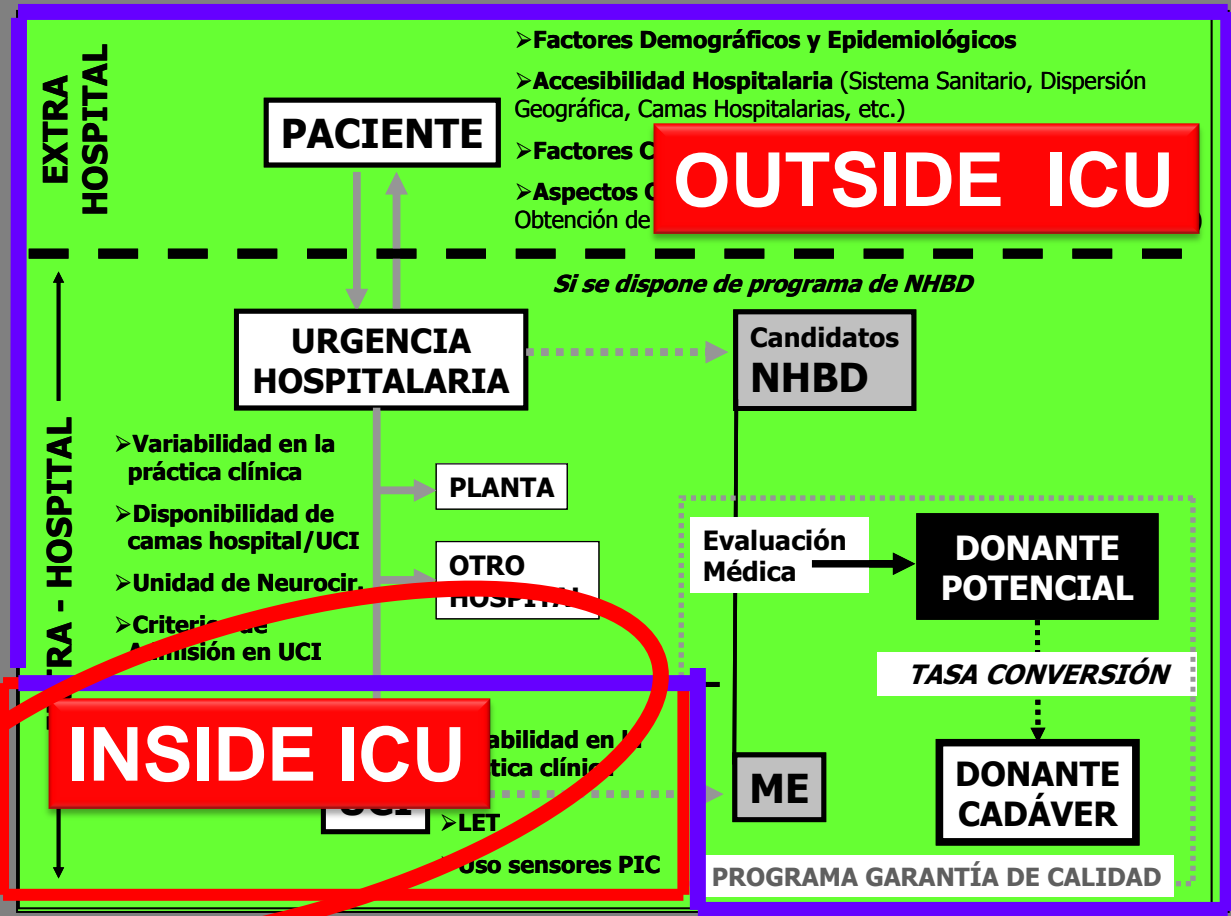
**GREAT NETWORKING OPPORTUNITIES BETWEEN CRITICAL CARE AND ORGAN DONATION TEAMS**



Plans were implemented during 2013 & 2014 in 56 selected hospitals



**A LARGE IMPACT IN DAILY PRACTICE CAN BE EXPECTED FROM THIS IMPROVEMENT MODEL IN DAILY PRACTICE**



**FACTORS INFLUENCING THE NUMBER OF POTENTIAL ORGAN DONORS**



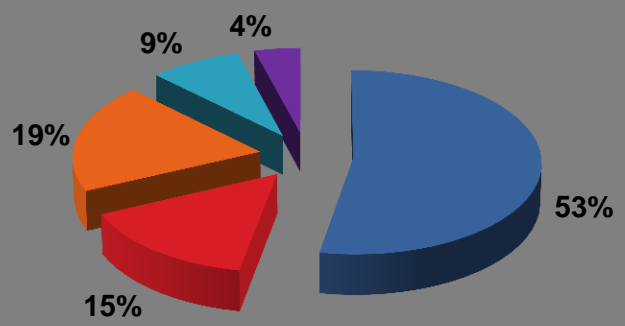
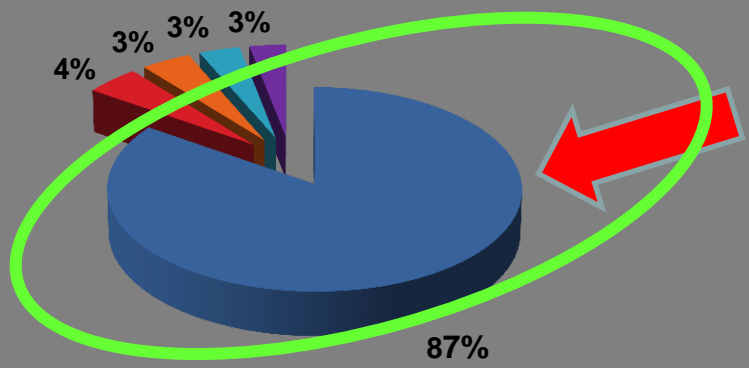


# TRANSPLANT COORDINATION TEAMS SPAIN – 2015 (N: 189)



- INTENSIVOS
- OTROS
- ANESTESIA
- NEFROLOGIA
- URGENCIAS

- INTENSIVOS
- OTROS
- A. QUIRURGICA
- NEFROLOGIA
- URGENCIAS



**MEDICAL DOCTORS = 270**  
**FULL TIME DEDICATED = 7 %**  
**PART TIME DEDICATED = 93%**

**NURSES = 168**  
**FULL TIME = 29 %**  
**PART TIME = 71 %**



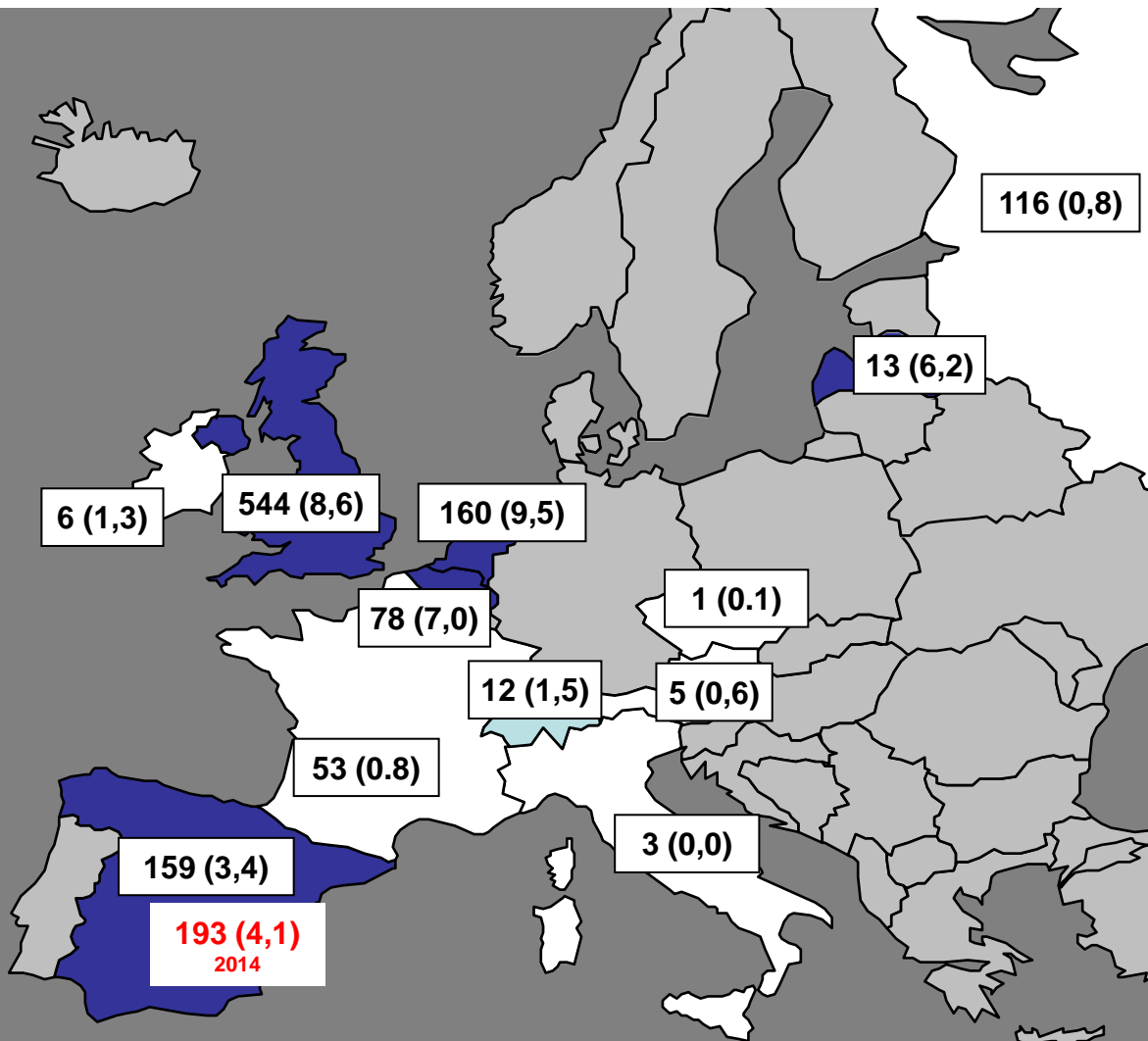
**BOTH ROLES FOR INTENSIVISTS:  
PROBABLY THE BEST SOLUTION**



**➤ 900 YOUNG INTENSIVISTS TRAINED IN ORGAN DONATION THROUGH THE ONT COURSES DURING THE LAST 8 YEARS**

# DCD DONORS IN EUROPE.

## TOTAL NUMBER / (pmp). 2013



- >3 pmp
- 1-3
- pmp
- < 1pmp

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2014

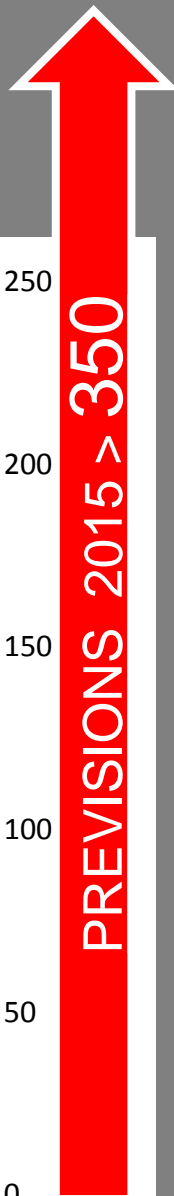
INTERNATIONAL FIGURES ON  
DONATION AND TRANSPLANTATION - 2013

NEWSLETTER  
TRANSPLANT





**GREAT INCREASE OF DCD DONORS**



Descienden los donantes 'clásicos' por la disminución de accidentes de tráfico y cerebrovasculares  
**Matesanz: "La donación a corazón parado es la vía de futuro de los trasplantes"**

Responsables de trasplantes de toda España asisten en el Centro Tecnológico de Formación del Hospital de A Coruña a un curso sobre donaciones en asistolia controlada

**María de la Huerta**  
A CORUÑA

La demanda de órganos supera la oferta. Y aunque el modelo español de trasplantes es referente mundial, siempre hay margen de mejora, tal y como reconoció ayer el director de la Oficina Nacional de Trasplantes (ONT), Rafael Matesanz, quien destacó que los donantes que fallecen por parada cardíaca "son, probablemente, la principal vía de expansión, el futuro", para lograr mantener el número de intervenciones, debido al descenso progresivo de los donantes en muerte encefálica. "Los donantes clásicos, en muerte encefálica, tienden a disminuir por el descenso de los siniestros de tráfico, y también de los accidentes cerebrovasculares, gracias a un mejor control de factores como



Antón Fernández, Jacinto Sánchez, Rafael Matesanz y Francis Dolmonico, ayer, en A Coruña. / 13/01/08



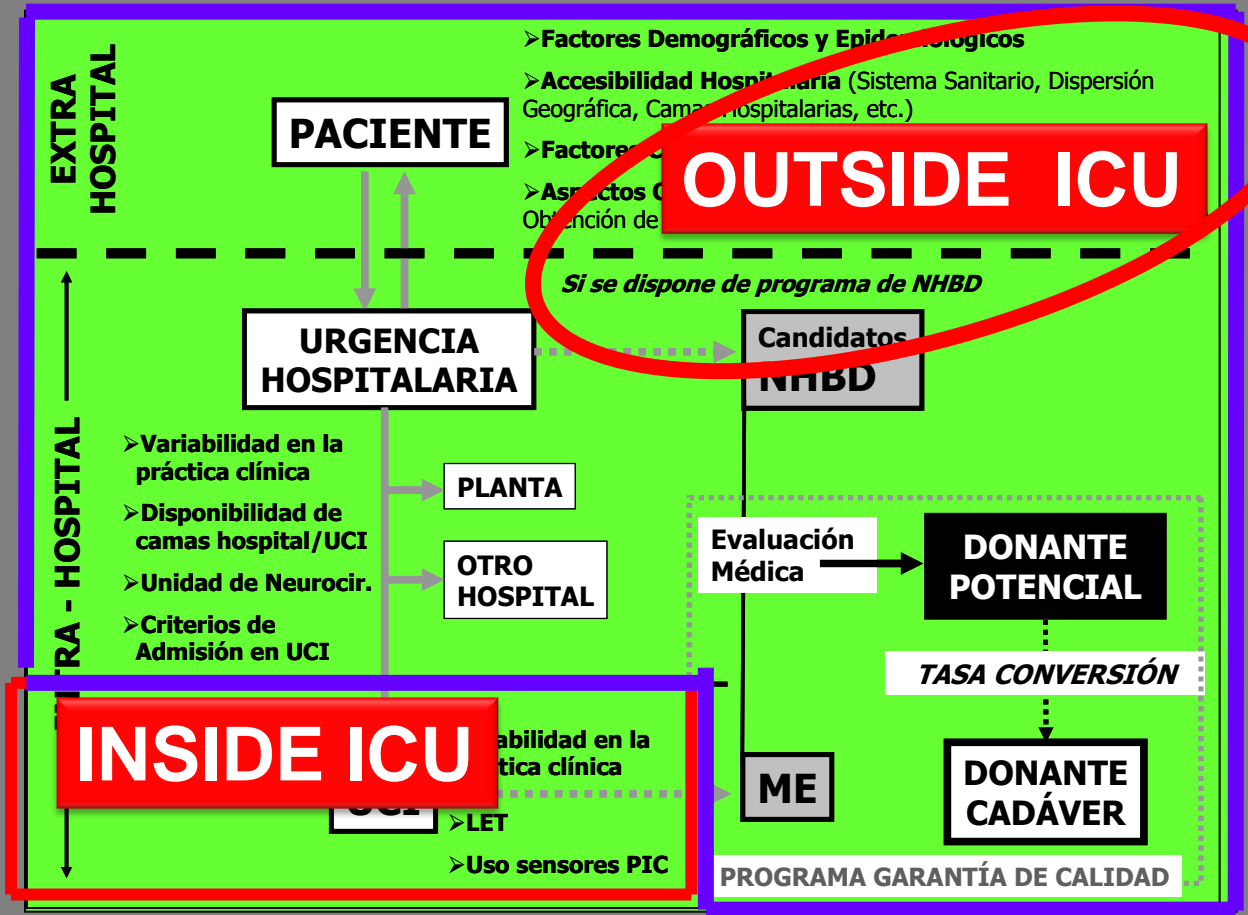
FUNDACIÓN MUTUA MADRILEÑA

23 de Noviembre 2011  
AUDITORIO FUNDACIÓN MUTUA MADRILEÑA, MADRID

**CONFERENCIA DE CONSENSO NACIONAL SOBRE DONACIÓN EN ASITOLIA**

Directores:  
Rafael Matesanz  
Eduard Domínguez Gil  
Elisabeth Coll





**FACTORS INFLUENCING THE NUMBER OF POTENTIAL ORGAN DONORS**

TRASPLANTES SEGÚN RAFAEL MATESANZ

**El profesional de urgencias es el eslabón para aumentar las donaciones de órganos**

**El Lareto Mármol**  
 Rafael Matesanz, director de la Organización Nacional de Trasplantes (ONT), con accidentes cerebrovasculares (más de las dos terceras partes de los donantes).





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## RECOMENDACIÓN 11:

THE EXISTENCE OF A PROGRAM SPECIFICALLY ORIENTED TOWARDS THE TREATMENT OF THE NEUROCRITICAL PATIENT IMPROVES THE EFFECTIVENESS OF THE REFERRAL OF POSSIBLE DONORS TO THE CRITICAL CARE UNITS (CCU)

Addressed to:  
of Units outside  
severe brain  
Transplant Co

Recommendation 11.1:

In the development, implementation and maintenance of said program, all of units outside the CCU attending to patients with severe brain damage must be involved

Addressed to:  
Responsible

Recommendation 11.2:

In the CCUs, it is essential to generate the habit of decisions based on discussion and consensus in regards to the management for each patient, in general, and in regards to the neurocritical patient and possible donor, specifically

Addressed to: RECOMMENDATION 12:

Generating d  
a consensus c  
all of the CCU

THE DEVELOPMENT OF TRAINING, PROMOTIONAL, AND EDUCATIONAL ACTIVITIES ON DONATION AND TRANSPLANTATION AIMED AT THE PROFESSIONALS OF THE CCU AND OF THE UNITS OUTSIDE OF THE CCU THAT ATTEND TO NEUROCRITICAL PATIENTS IS RECOMMENDABLE

Addressed to: Hospital Administration; CCU Responsible Person; Responsible Persons of the Units outside of the CCU attending to patients with serious brain damage; Hospital Transplant Coordination

GOOD PRACTICE GUIDELINES IN THE PROCESS OF ORGAN DONATION



# Recommendations



IV

To improve the effectiveness of the referral of the possible donors to the critical care units

**12 RECOMMENDATIONS**



Good Practice Guidelines

in the process of Organ Donation



GOBIERNO DE ESPAÑA

MINISTERIO DE SANIDAD, POLÍTICA SOCIAL E IGUALDAD



# TRAINING COURSES IN ORGAN DONATION FOR EMERGENCY DOCTORS : ONT – SEMES SINCE 2009

ÓRGANOS 2.000 PROFESIONALES EN 4 AÑOS

## Acuerdo de la ONT y Semes en formación e investigación



Rafael Matesanz, de la ONT.

**J.J.M.J.**  
La Organización Nacional de Trasplantes (ONT) y la Sociedad Española de Medicina de Urgencias y Emergencias (Semes) firmaron ayer un convenio que amplía la colaboración docente que mantienen desde hace tres años a otros campos como la investigación.  
El nuevo acuerdo, que extenderá la formación de profesionales de urgencias en donación y trasplante de órganos a todo el Sistema Nacional de Salud, se ha rubricado por una duración inicial de cuatro años, durante los cuales la ONT y Semes calculan que pueden formar al menos a 2.000 profesionales.  
Andalucía, Castilla y León, Cataluña, Galicia, Extremadura, Madrid y el País Vasco impartirán en los pró-

práctica que la ONT destacó en su guía de buenas prácticas (ver DM del 5-I, del 25-II y del 5-VII-2011).  
Rafael Matesanz, director de la ONT, ha manifestado su satisfacción por el acuerdo alcanzado por significar un paso más hacia la implicación de todos los profesionales en el proceso de la donación y hacia la aplicación de la guía una vez comprobado que los resultados obtenidos en los hospitales en los que existe la figura del coordinador de trasplantes en los servicios de urgencias son mejores. Además, el acuerdo "permitirá precisar la medición de la actividad en los centros y conocer el potencial que tenemos en donación en parada cardíaca, algo que hasta ahora no conocemos".  
También satisfecho, To-



CURSOS URGENCIAS	2009	2010	2011	2012	2013	2014	2015	Total
Castilla y León	1	4	3	4	4	2	2	20
Cataluña	1	3	4	4	4	1	1	18
Galicia			5	5	4	2	1	17
Andalucía			2	13	1		3	19
Madrid			6	5	5		3	19
Extremadura				5	5	2	1	13
Aragón				2	3	4	1	10
País Vasco				1	1		2	4
Baleares				1	1	1	2	5
Castilla la Mancha					1	1	2	4
Canarias					1		1	2
Asturias						1		1
C. Valenciana						1	3	4
C. Foral de Navarra							1	1
Murcia							1	1
<b>TOTAL POR AÑOS</b>	<b>2</b>	<b>7</b>	<b>20</b>	<b>40</b>	<b>30</b>	<b>15</b>	<b>24</b>	<b>138</b>

**138**  
COURSES  
IN 15 REGIONS



➤ **5000** EMERGENCY DOCTORS TRAINED DURING THE LAST SEVEN YEARS



# OPORTUNIDADES PARA LA MEJORA EN EL PROCESO DE LA DONACIÓN: RESULTADOS ESPAÑOLES DE UN ESTUDIO MULTICÉNTRICO EUROPEO (17 SPANISH HOSPITALS)

**Beatriz Domínguez-Gil<sup>1</sup>, Teresa Pont<sup>2</sup>, Eduardo Miñambres<sup>3</sup>, Miguel Lebrón<sup>5</sup>, Álvaro García-Miguel<sup>6</sup>, Carlos Fernández-Renedo<sup>7</sup>, José M<sup>a</sup> Sánchez-Andrade<sup>9</sup>, Pablo Ucio<sup>10</sup>, M<sup>a</sup> Sol Martínez-Mingall<sup>11</sup>, Pedro Enríquez<sup>13</sup>, Ana Carolina Caballero<sup>14</sup>, Kepa Esnaola<sup>15</sup>, Carme Esther Corral<sup>17</sup>, Antonio Isusi<sup>18</sup>, Elisabeth Coll<sup>1</sup>, Rosario Marazuela<sup>1</sup>, Lolita Mesanz<sup>1</sup>**

**SPANISH CONTRIBUTION TO THE EUROPEAN PROJECT**

<sup>1</sup>Organización Nacional de Trasplantes, Madrid; <sup>2</sup>Hospital General de Galdakao, Galdakao; <sup>3</sup>Hospital Marqués de Valdecilla, Santander; <sup>4</sup>Donostia Ospitalea, Donostia; <sup>5</sup>Hospital General de Catalunya, Barcelona; <sup>6</sup>Hospital Regional Carlos Haya, Málaga; <sup>7</sup>Hospital Clínico Universitario, Salamanca; <sup>8</sup>Complejo Asistencial Universitario de León, León; <sup>9</sup>Complejo Asistencial Universitario de Burgos, Burgos; <sup>10</sup>Hospital Clínico Universitario de Valladolid, Valladolid; <sup>11</sup>Hospital General Universitario de Ciudad Real, Ciudad Real; <sup>12</sup>Hospital General de Segovia, Segovia; <sup>13</sup>Hospital Río Hortega, Valladolid; <sup>14</sup>Hospital Virgen de la Concha, Tordesillas; <sup>15</sup>Hospital de Cruces, Baracaldo; <sup>16</sup>Complejo Hospitalario La Mancha Centro, Alcázar de San Juan; <sup>17</sup>Hospital de Cruces, Vitoria; <sup>18</sup>Complejo Asistencial de Ávila, Ávila.

