

## European activities in the field of Organ donation and transplantation

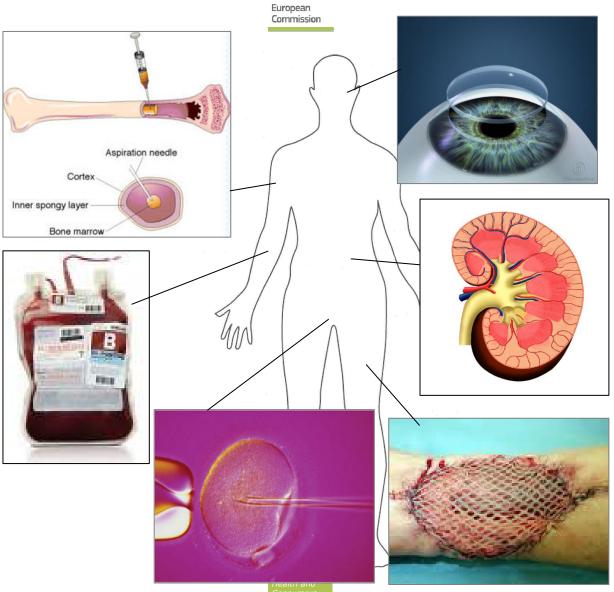
Journalist Workshop on Organ donation and transplantation 7 October 2013

Hélène Le Borgne Policy officer for Organ donation and transplantation Directorate General for Health & Consumers - European Commission





## Substances of human origin ("SoHO")



3 sectors explictly mentioned in the Treaty as « SoHO »:

→Blood and blood derivatives

→ Tissues and cells

#### **→Organs**

- kidneys
- livers
- hearts
- lungs
- pancreas
- small bowel



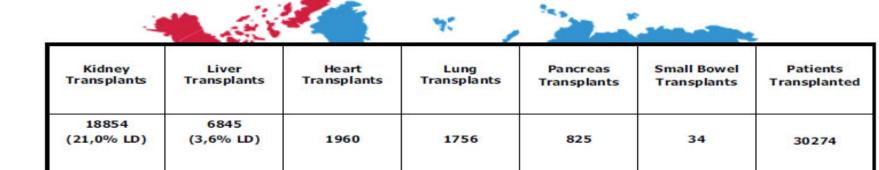
#### Organ Transplants in the European Union -2012







#### **EUROPEAN UNION DATA**



9637 ACTUAL DECEASED ORGAN DONORS (both DBD and DCD included)

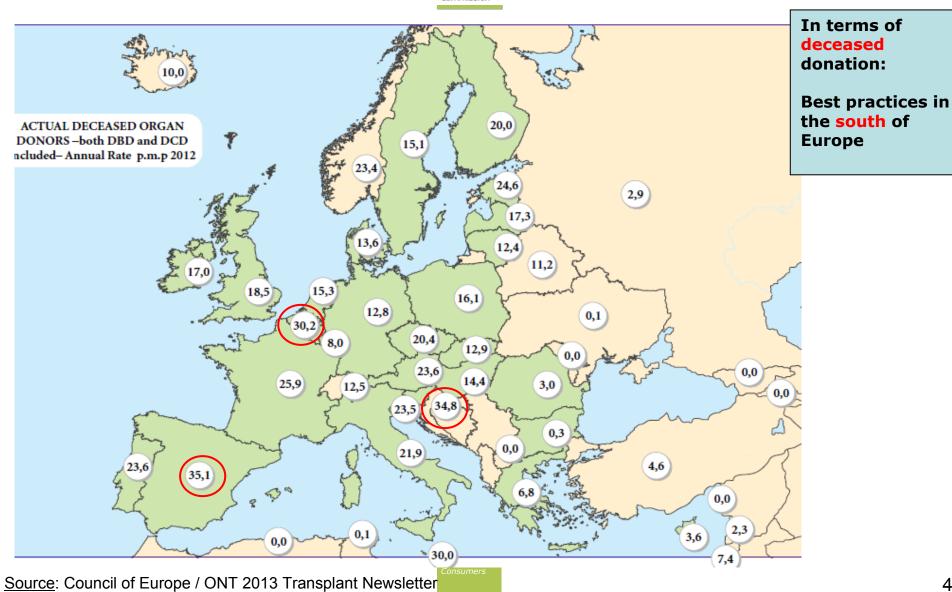
\*2012 data

N= 27 COUNTRIES (503,1 million inhabitants)





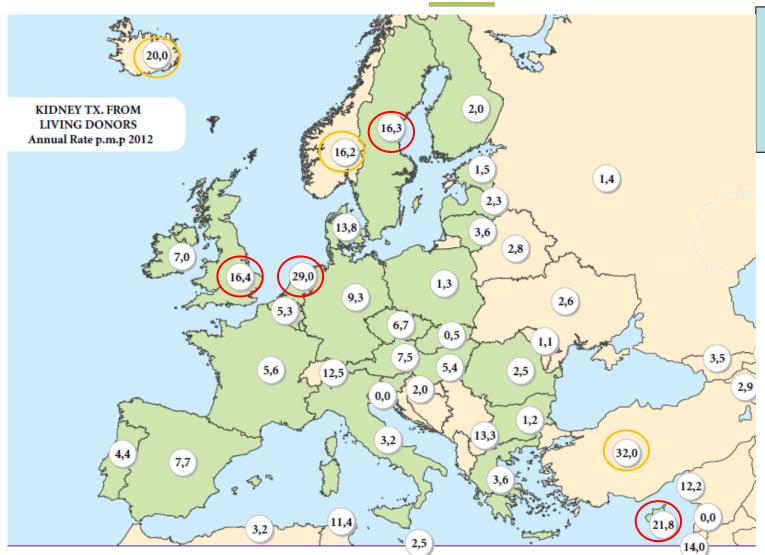
## **Deceased** organ donors - 2012





## **Kidney transplants from living donors – 2012**

European Commission



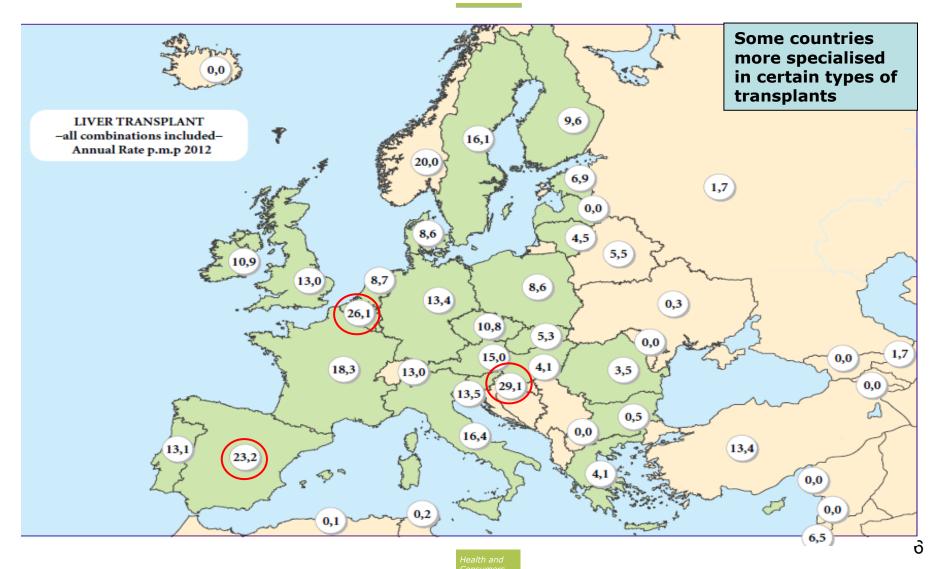
In terms of living donation:

Best practices in the north of Europe + Cyprus, Turkey

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## **Liver** transplants – 2012



Source: Council of Europe / ONT 2013 Transplant Newsletter

## \*\*\*\* European

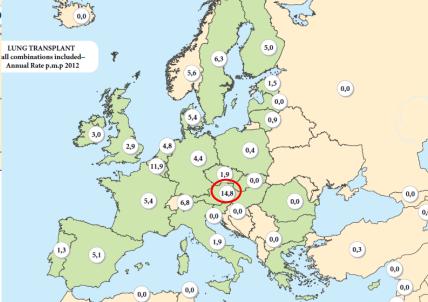
## **Heart, lung...** transplants - 2012

Commission HEART TRANSPLANT -all combinations included-Annual Rate p.m.p 2012 0,9 2,1 6,6 5,3

Not all countries have all types of transplant programmes

- →Bilateral or multilateral agreements between countries can be useful:
- to exchange organs
- to treat patients
- also better chances for a good « match » between donor organ and recipient
- to support building own capacities (twinning)

Eurotransplant (8 countries), Scandiatransplant (5) and South Alliance for Transplant (3) are European Organ Exchange Organisations



Health and Consumers



## **European Commission's legal mandate**

**Article 168** of the Treaty on the Functionning of the European Union: "setting **high standards of <u>quality</u> and <u>safety</u> of organs** and substances of human origin, blood and blood derivatives"

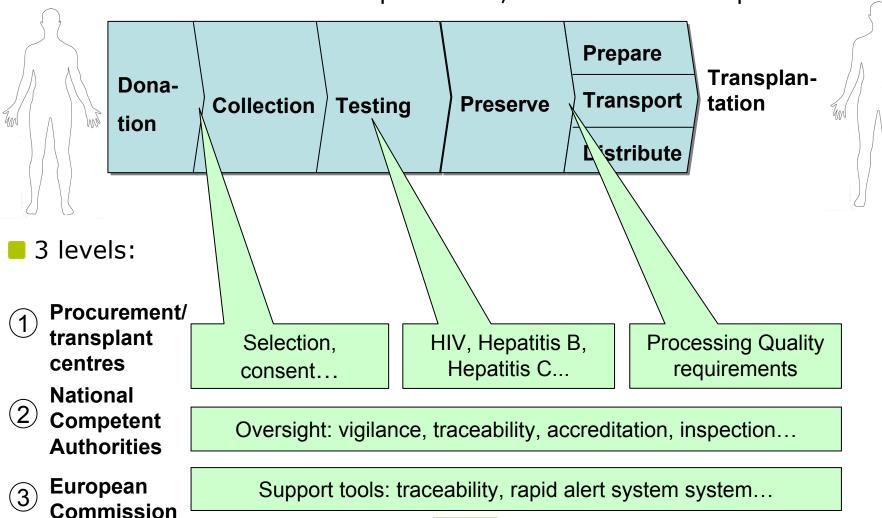
- Directive 2010/53/EU of the European Parliament and Council on standards of quality and safety of human organs intended for transplantation
  - Adopted on 7 July 2010
  - To be transposed by into national laws by 27 August 2012
  - Establish/consolidate « National Competent Authorities » (NCAs) in charge of the quality and safety framework
  - NCAs meet twice a year in Brussels, participate in EU-funded projects..
- Commission Implementing Directive 2012/25/EU laying down information procedures for the exchange, between Member States, of human organs intended for transplantation
  - Aligns communications on organ characterisation (offering), traceability and alerts
  - Adopted on 9 October 2012
  - To be transposed by into national laws until 9 April 2014





## Directive 2010/53/EU **Key elements for quality** and safety

• Chain from donation to transplantation, from donor to recipient



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## Directive 2010/53/EU Outside the scope

- The following areas are **outside of the scope of the Directive:** 
  - Consent systems (opt-in / opt-out)
  - Waiting lists
  - Allocation criteria
  - Legislation around brain death
  - Health systems and resources
  - → The areas remain **national competence**
  - → However, the Commission can encourage Member States to share experiences through collaboration under the Action Plan (voluntary tool)



- International cooperation (Council of Europe, WHO)
- Activities under the **Action Plan on organ donation and transplantation (2009-2015)** (a Communication from the Commission adopted in December 2008) 3 main objectives:
  - → increase organ availability
  - → improve transplant systems (efficiency and accessibility)
  - → improve quality and safety
- **Tools** at disposal under the Action Plan:
  - → Projects funded under the EU Health Programme
  - → Working groups:
    - →deceased donation (Manual on how to set a system of transplant donor coordination)
    - →indicators
    - →living donation
  - **→** Journalists Workshops

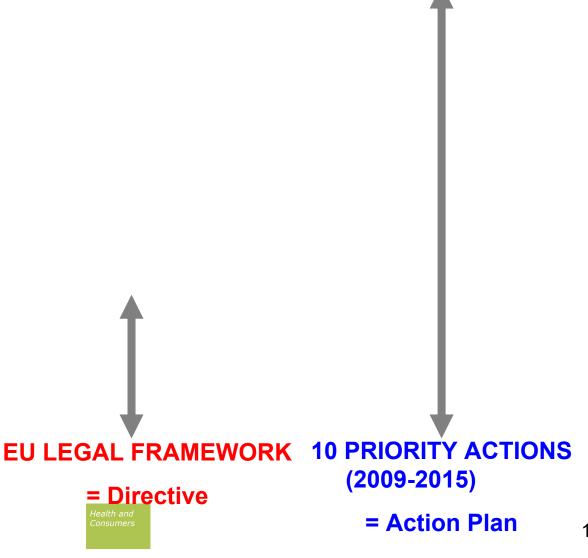




Increasing organ availability

Make transplantation systems more efficient and accessible

1 Improve quality and safety





## **The Action Plan** (2009-2015)

1 transplant coordinators Halfway 2009-2015: Increase 2 quality improvement programmes Mid-term review Organ 3 living donation programmes of the Action Plan **Availability** 4 communication skills of professionals **ACTIONS** 5 information on citizens rights - Council Conclusions adopted on 7 December 2012 **OBJECTIVES** by EU Health **Enhance** Ministers **Efficiency PRIORITY** 6 enhance organisational models and - Study on the 7 EU-wide agreements **Accessibility of** uptake of the action 8 interchange of organs plan, financed by **Transplantation** the Commission **Systems** under the EU Health 9 Programme (ACTOR study) Quality 9 evaluation of post-transplant results and 10 common accreditation system Safety

Council conclusions: <a href="http://ec.europa.eu/health/blood\_atissues">http://ec.europa.eu/health/blood\_atissues\_organs/docs/organs\_council\_ccl\_2012\_en.pdf</a>
ACTOR study: <a href="http://ec.europa.eu/health/blood\_tissues">http://ec.europa.eu/health/blood\_tissues\_organs/docs/organs\_actor\_study\_2013\_en.pdf</a>



Projects database: <a href="http://ec.europa.eu/eahc/projects/database.html">http://ec.europa.eu/eahc/projects/database.html</a>

- Project: "Train the trainers in transplant donor coordination" (2011)
  - for national/regional/local trainers (80 participants from all Europe)
  - to increase organ availability
- Joint action ACCORD Assisting Member States in reaching the full potential of deceased and living donation (2012-2015)
  - Collaboration between transplant coordinators and intensive care units
  - Registers for living donors
  - Twinning programmes
- Project to support cross-border exchanges: FOEDUS Facilitating exchange of organs donated in EU Member States (2013-2016)
  - further develop an IT tool to offer organs cross-border
  - encourage cross-border agreements to facilitate organ exchanges
  - agree on communication strategies

Also: COORENOR, EDD, EULID, ELIPSY, EFRETOS, ODEQUS... projects See in the press pack: "useful links"

Also **Research projects** funded under the Framework Programmes (FP6, FP7): DOPKI, Alliance-O, RISET, HepaMab, The ONE study, COPE...

#### Life after death

The Flemish non-profit Navado brings relatives of organ donors together in times of grief



On 28 February, 2000, the Var Kempen family Experienced IX darkest day: Eighty-year-old Keily fell down the stairs while playing with her two sisters. Keily's mother, Us, drove straight to the hospital, where doctors told her that Keily was already dead.

terrible news, the doctors asked Lia and her husband, Erick, if they would allow Kelly's organs to be donated. "We knew we couldn't do arrything more for Kelly and that by allowing organ donation we could maybe give

other children a chance to survive," says Lia Van Kempen now, 12 years after she lost her daughter. "So we mmediately gave our permission. After that, the doctors to it of us about the donation procedure, but because we were still overcome by sadness, that information didn't get through to us."

#### Strength and support

A couple of weeks later, when Keily's parents were slowly trying to come to terms with what had happened, they found the business card of Walter van Donink, the transplant co-ordinator at the hospital where their daughter had died.

"We met him several times, and he explained all the details of the complicated organ donation procedure," says



Organised in Brussels by Commission in 2010, 2011, 2012... and today

# - Journalists Workshop ORGAN DONATION AND TRANSPLANTATION an invitation of The European Commission

**Journalist Workshops** 

**Objective:** increase public awareness of organ donation (offering different views, facts&figures, testimonies...)

Linked to EU Action Plan (PA 4) and organised ahead of **European Organ Donation Days (EODD)** co-organised by Council of Europe and hosting country (Belgium in 2013, Hungary in 2012...) <a href="http://eodd2013.be/">http://eodd2013.be/</a>

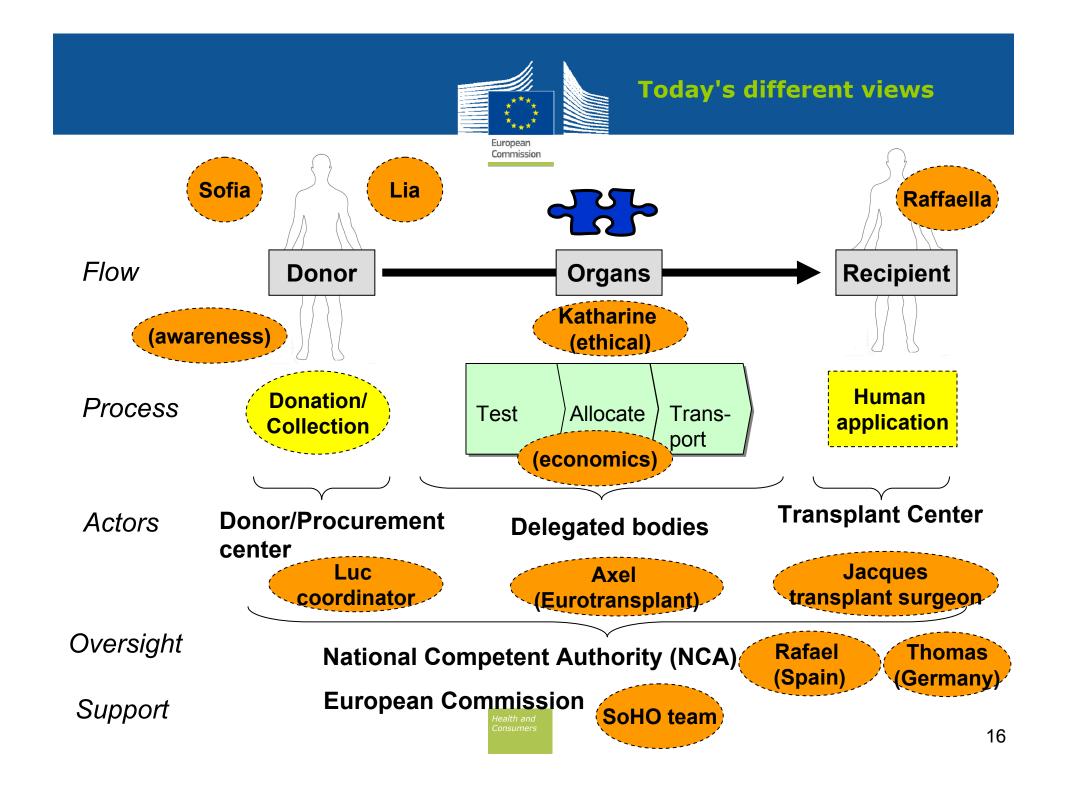
**Participation**: totally 113 journalists from 28 countries

- → articles/press releases/videos after the 3 first editions published on our website (and translated)
- →and articles submitted under the **EU Health Prize for Journalists** <a href="http://ec.europa.eu/health-eu/journalist\_prize/">http://ec.europa.eu/health-eu/journalist\_prize/</a>

Articles from the previous Workshops on our website: <a href="http://ec.europa.eu/health/blood tissues organs/events/journalist\_workshops organ\_en.htm#fragment1">http://ec.europa.eu/health/blood tissues organs/events/journalist\_workshops organ\_en.htm#fragment1</a>

→ Please send us your articles after publication





## In the press pack ... and on the website





#### **2013 Journalist Workshop:**

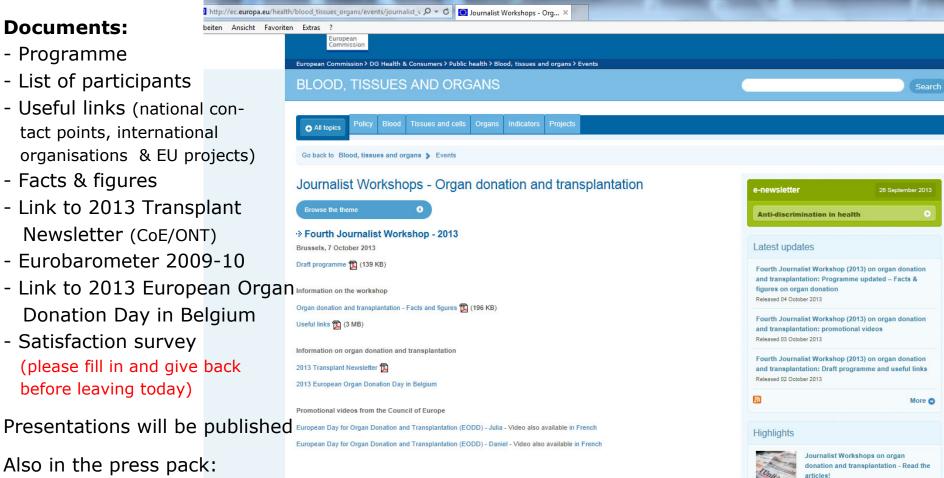
http://ec.europa.eu/health/blood tissues organs/events/journalist workshops organ en.htm http://ec.europa.eu/health/blood tissues organs/organs/ Policy:

#### **Documents:**

- Programme
- List of participants
- Useful links (national contact points, international organisations & EU projects)
- Facts & figures
- Link to 2013 Transplant Newsletter (CoE/ONT)
- Furobarometer 2009-10
- Link to 2013 European Organ Information on the Workshop Donation Day in Belgium
- Satisfaction survey (please fill in and give back before leaving today)

Also in the press pack:

- Directives, Action Plan, Council conclusions



## Our team for "Substances of human origin" (SoHO)



#### http://ec.europa.eu/health/blood tissues organs/policy/index en.htm

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Alina Cornea (SoHO, meeting support)

<u>Stefaan Van der Spiegel</u> (SoHO, team coordination)

<u>Dominik Schnichels</u> (SoHO&Tobacco control, head of unit)

Commission

#### THANK YOU!

