

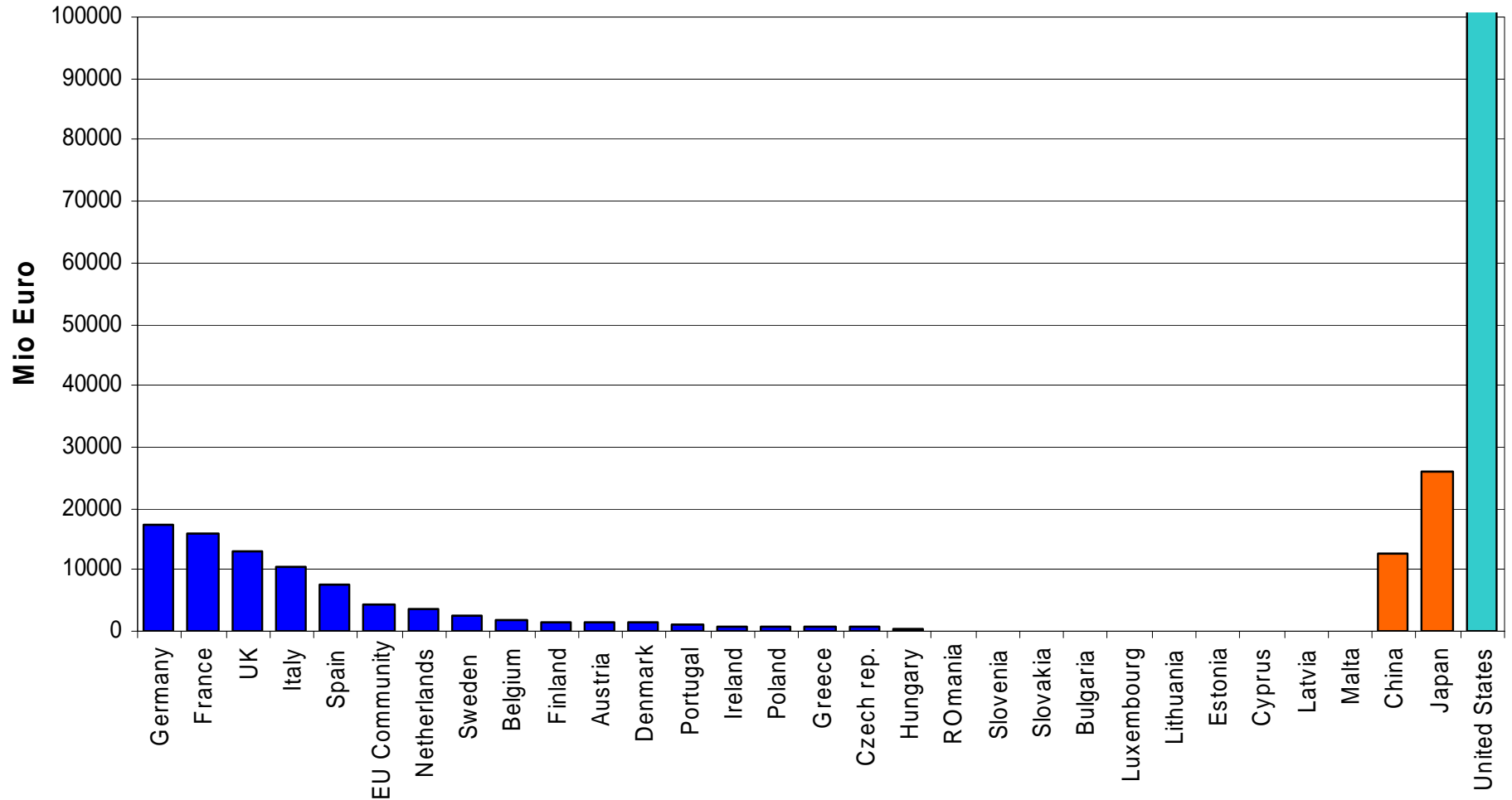
## European Collaboration on Dementia Research The Joint Programming Initiative

**Prof. Philippe Amouyel**  
JPND, Chair

**On behalf of the Management Board of JPND**

# A fragmented ERA

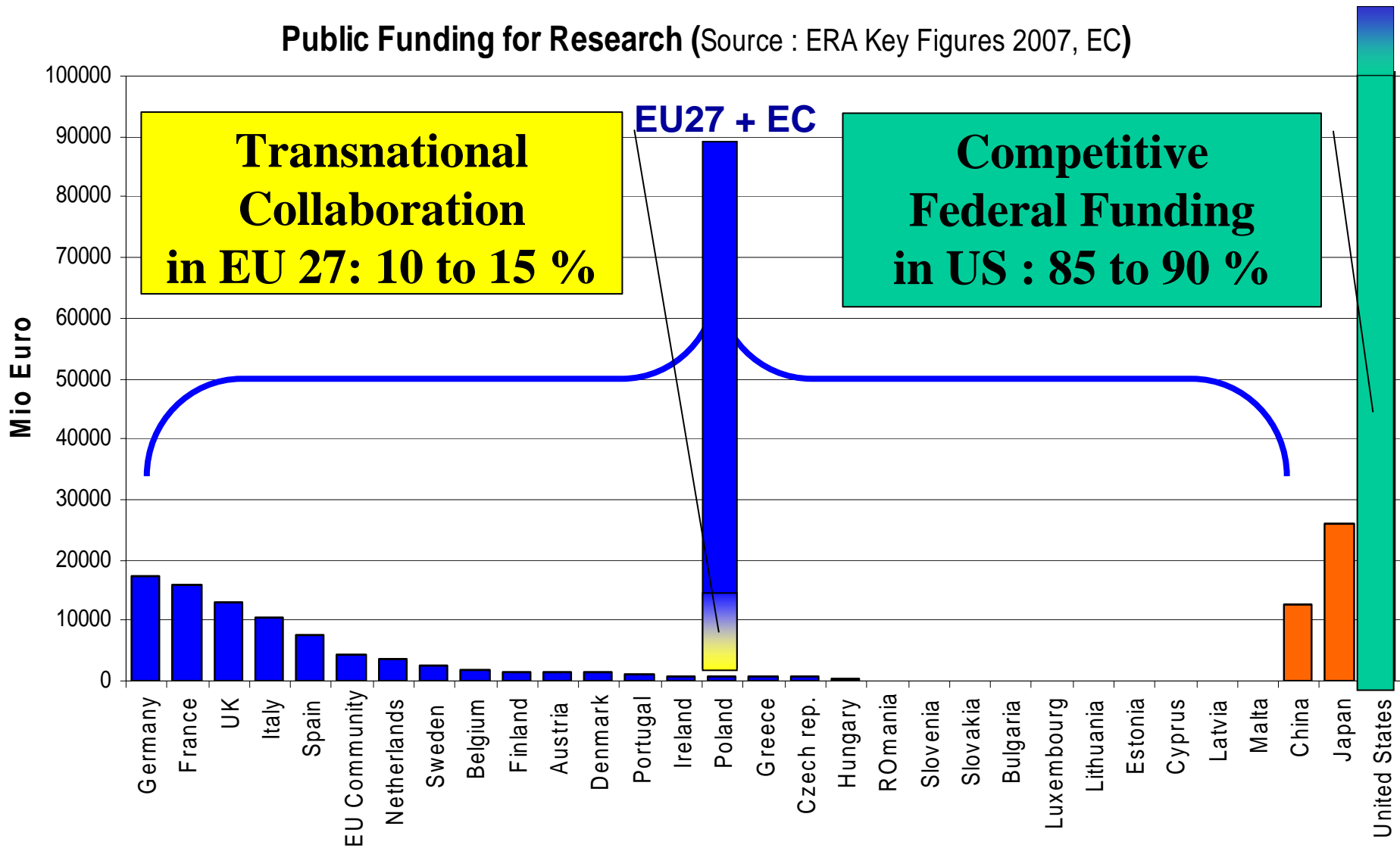
**Public Funding for Research** (Source : ERA Key Figures 2007, EC)





# A fragmented ERA

**Public Funding for Research (Source : ERA Key Figures 2007, EC)**





**JPND**

research

EU Joint Programme – Neurodegenerative Disease Research

# Joint programming perspectives and motivation

- Harmonizing strategic research approaches within countries to tackle more efficiently societal challenges
- Synergistic use of shrinking research budgets in a difficult economic climate
- Grouping calls for grants at the level of several member states on a voluntary basis will reinforce the potential for scientific collaboration in Europe
- Accountability to stakeholders in pooling research efforts addressing common social issues in Europe
- Simplifying European procedures governing scientific collaboration (and its administration)

# Joint Programming a definition

- Member States engaging
  - voluntarily and on a variable geometry basis to tackle a major societal question
  - in the definition, development and implementation of common strategic research agenda
  - based on a common vision on how to address major societal challenges.
- It may involve collaboration between existing national programmes or the setting up of entirely new ones.
- It entails putting resources together,
- selecting or developing the most appropriate instrument(s)
- collectively monitoring and reviewing progress.

## What it is not...

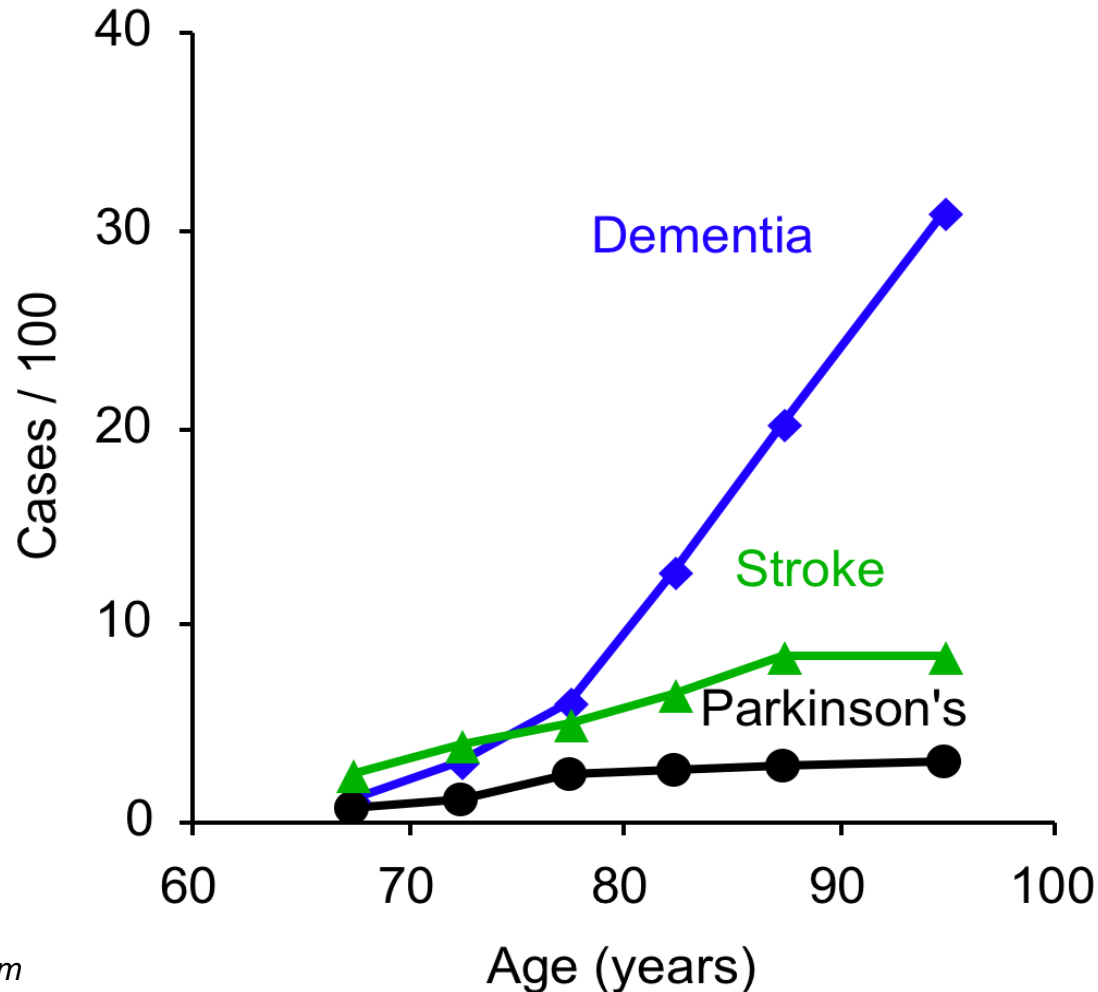
- It is not a new tool
- It is not about increasing administrative burden
- It is not about asking for more money from the Framework Programme
- It is not about asking for more power at EU level
- It is not a new instrument for Community research
- It is not about spending the money, but about assigning the money

- 1. A shared vision**
- 2. A common Strategic Research Agenda**
- 3. A Management Structure**
- 4. State of play**

## 1. A shared vision



# Prevalence of Neurodegenerative Diseases





**JPND**

research

EU Joint Programme – Neurodegenerative Disease Research

# **Neurodegenerative diseases and Alzheimer's disease in particular :**

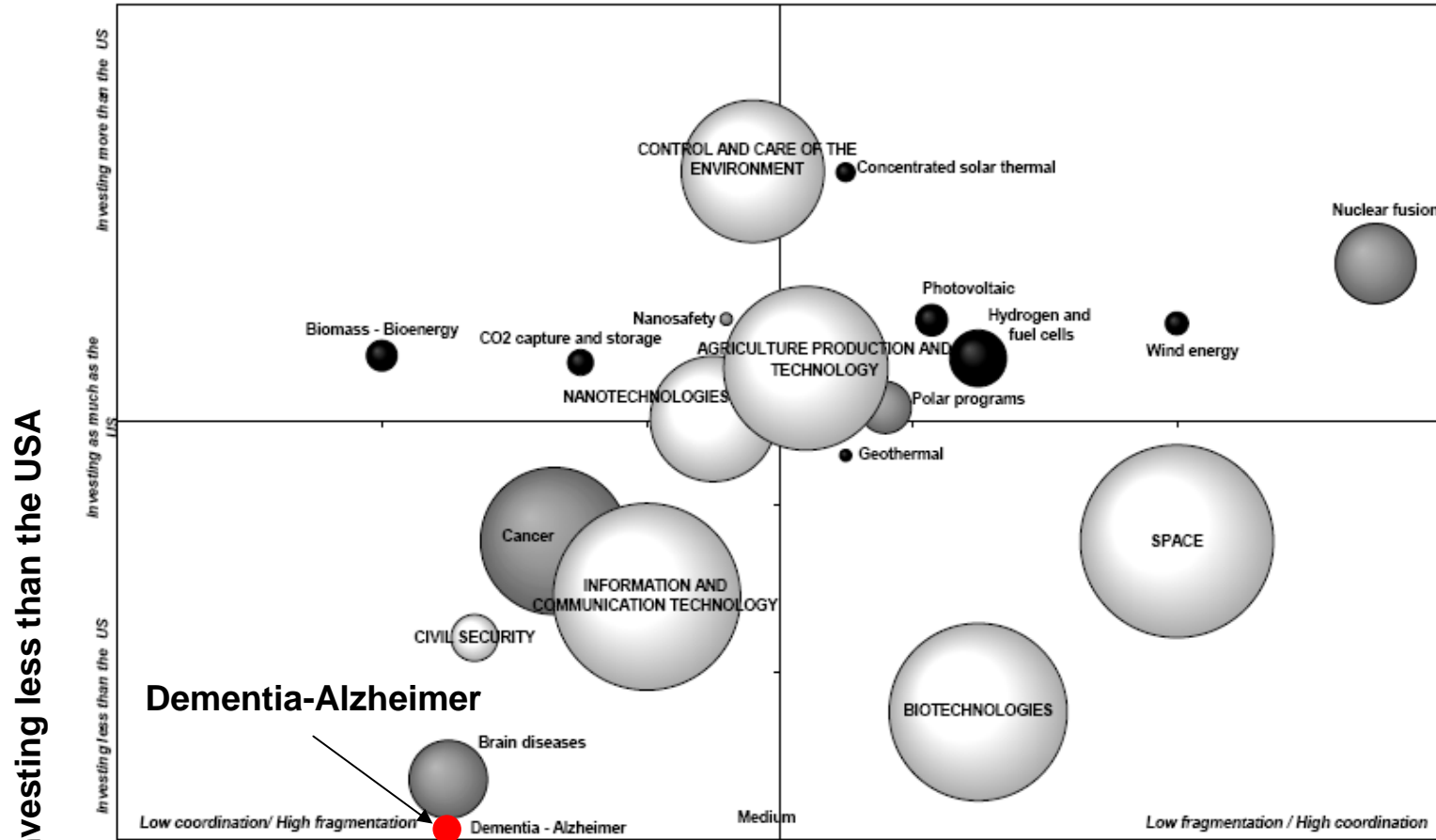
**a major societal challenge for  
the coming years**



**JPND**  
research

EU Joint Programme – Neurodegenerative Disease Research

# A diversity of publicly funded research in the European Research Area



Low coordination / High fragmentation

From EU COM (2008) 468

## 2. Towards a common strategic research agenda

# Taking the disease into account in all its dimensions

**To mobilise the best researchers from all fields, to develop the sharing of best practices and know how**

- A scientific challenge
- A medical challenge
- An ethical and social challenge

# Building the Strategic Research Agenda

- Identify research priorities with a Scientific Advisory Board (SAB) composed of 15 of the best scientists equally distributed between domains
- Mapping the research field at National and European levels
- Organize ad-hoc groups to detail each scientific priority finally retained by the SAB
- Identify the gaps to bridge
- Organize a list of priorities to implement
- Facilitate an “à la carte” organization allowing each member of the JP to participate actively

# Scientific Advisory Board



# Scientific Advisory Board

- **Basic research**

John Hardy (UK)  
Thomas Gasser (D)  
Jesus Avila de Grado (S)  
Bart de Strooper (B)  
Leszek Kaczmarek (PL)

- **Clinical research**

Bengt Winblad (SW)  
Martin Rossor (UK)  
Philip Scheltens (NL)  
Bruno Dubois (F)  
Stefano Cappa (I)

- **Main missions:**
- **To help designing the SRA** (before the first quarter 2011)
- **To suggest urgent scientific priorities to support in the mean time as « case-study »**

- **Health Care and Social research**

Laura Fratiglioni (SW)  
Henry Brodaty (Australia)  
Martin Knapp (UK)  
Jesus de Pedro Cuestas (S)  
*TBA*



## 3. Designing a management structure

# General Composition

- Representatives able to take strategic decisions with sufficient authority to commit funds at a national level
  - ➔ President : Philippe Amouyel, **France**
  - ➔ Vice President : Maria Wästfelt, **Sweden**
  - ➔ Executive board : Adriana Maggi, **Italy** ; Enda Connolly, **Ireland**; Eckhart Curtius, **Germany**
  - ➔ Steering committee : + Rob Buckle, **UK** ; Edvard Beem **Netherlands** ; Didem Celikkanat Ozan, **Turkey** ; Birgit Wetterauer **Germany**
- On a voluntary basis
- Open to new participants

## 4. State of Play



# JPND

research

EU Joint Programme – Neurodegenerative Disease Research

## 23 Participants

- **Albania**
- **Belgium**
- **Czech Republic**
- **Denmark**
- **Finland**
- **France**
- **Germany**
- **Greece**
- **Hungary**
- **Ireland**
- **Italy**
- **Luxemburg**
- **The Netherlands**
- **Norway**
- **Poland**
- **Portugal**
- **Slovak Republic**
- **Slovenia**
- **Spain**
- **Sweden**
- **Switzerland**
- **Turkey**
- **United Kingdom**

- **Mapping of National and European research programmes**
- **Definition of strategic and scientific priorities that would benefit from coordination at the European level**
- **Definition of framework conditions to implement the SRA, i.e. political, legal, regulatory and financial arrangements**
- **Implementation of joint and coordinated research activities responsive to stakeholder interests**
- **Engagement of stakeholders through a communication plan to ensure the ultimate translation of research outputs into practice and policy**
- **Evaluation and monitoring of the joint activities**

# Preliminary mapping Results

- National research strategy, initiatives and funders in the ND/AD area:
  - 4 countries have a bottom-up approach to raise programmes and initiatives : **BE, FI, TR, PL**;
  - 1 country has a top-down approach to support programmes and initiatives : **IT**
  - 9 countries have a national research strategy for ND/AD: **CZ, FR, DE, NO, PT, ES, TR, UK, GR**;
  - remaining countries: no specific national plan for ND/AD research.
- At European level:
  - All together, the EC has financed ND/AD research through different programmes for an amount of approximately 225 million €.
- A final mapping is being prepared through a detailed web based consultation of each MB members who nominated a specific correspondant for this mapping

- **Workshops will be organized by the SAB to prepare the SRA between January and April**
- **Three one day thematic workshops**
  - ➔ Basic Research (Madrid)
  - ➔ Clinical Research (Paris)
  - ➔ Social Healthcare (London)
- **One two day final workshop**
  - ➔ With stakeholders the first day
  - ➔ SAB the second day
- **A first draft of the SRA will be circulated to the MB members**
- **The SRA will be open to “public” discussion through a web consultation**
- **The SRA will be adopted during the first half of 2011**

# SAB/SC proposals

- During its first meeting in Stockholm (15th-16th April 2010) the SAB proposed 4 possible urgent topics to be implemented as soon as possible
- While the SRA preparation will progress, these 4 proposals may be concrete example to implement to identify and overcome practical limitations of JP
- These proposals have been submitted to the MB in June
- The EB/SC with the SAB is working on these 4 proposals to prioritize and suggest possible implementation plan for the next MB meeting in October in Berne



- Harmonize determination of CSF-biomarkers for Neuro-degeneration across Europe
- Whole exome sequencing of cases of neurodegenerative diseases
- Multidimensional intervention in cognitively impaired persons
- New avenues for drug discoveries in Alzheimer's disease

# Framework conditions of the individual participating members

- Participation to transnational joint calls:
  - Nearly all Member states already participate in such initiatives (ERA-net, Ambient Assisted Living, article 169, bilateral calls...).
- All MB members wish to participate in the JP initiatives, provided that
  - Process is transparent
  - Proposals are peer-reviewed
  - It is in line with their national research strategy
- Some Member States plan to have a common approach of JP
  - Discussion between ministries in Norway, Netherlands
  - Some countries already reserved funds (1 for 2010, 6 for 2011, 6 for 2012)



**JPND**  
JPND stands for  
Joint Programming  
Neurodegenerative  
Disease.  
Find out more in  
the ['About'](#) pages.

Home

## Home

---

### Neurodegenerative research

Welcome to the interim website for the Joint Programme in Neurodegenerative Diseases (JPND). This is a European Union member state-led initiative to tackle one of the 'grand challenges' which faces EU society, namely that of neurodegenerative diseases. Our first press release is shown below.

The Scientific Advisory Board (SAB) selected Thomas Gasser as Chair and Martin Rossor as Vice Chair.



**First pan-European 'joint programming research initiative' will tackle Alzheimer's and other neurodegenerative**



**JPND**

research

EU Joint Programme – Neurodegenerative Disease Research

**A new initiative around research excellence intended to offer a competitive and attractive image of European research carried out for the greatest benefit of Europe's populations and economies**