Joint Programming Initiative on Neurodegenerative Diseases

Prof. Philippe Amouyel
Chair, JPND Management Board
Alzheimer’s disease in Europe

A major societal challenge for the coming years

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of cases</th>
<th>Societal costs (€)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>6,000,000</td>
<td>72,000,000,000</td>
</tr>
<tr>
<td>2040</td>
<td>12,000,000</td>
<td>144,000,000,000</td>
</tr>
</tbody>
</table>
Population Projections and Ageing

More developed regions

Less developed regions

% of total population

Calendar year

Europe major societal « Grand Challenge »

- Energy
- Climate Change
- Food & Health
- Neurodegeneration
“to put the issue of neurodegenerative diseases in the top priorities of the agenda of the European Council.”

“to launch a joint programme of research on these diseases, combining socio-economic and medico-biological issues.”
What is Joint Programming?

National research programmes are not sufficient to address the societal challenge.

A new Member States-led initiative in Europe which aims to address “grand challenges” to EU society by coordinating national research programmes within the EU to increase the impact and effectiveness of research efforts.

JPND addresses the accountability of governments to stakeholders to address major societal issues by joining research forces and reducing fragmentation.
Joint Programming - a definition

European countries engaging

- voluntarily and on a variable geometry basis to tackle a major societal question

- in the definition, development and implementation of a common strategic research agenda

- based on a common vision on how to address major societal challenges.
What are the JPND goals?

To tackle the challenge of Alzheimer’s and other neurodegenerative diseases*, the goals of the JPND Research Strategy are:

- To develop new treatments and preventive strategies
- To improve health and social care approaches
- To raise awareness and de-stigmatise neurodegenerative disorders
- To alleviate the economic and social burden of these diseases

*Alzheimer’s disease and other dementias (AD), Parkinson’s disease (PD) and PD-related disorders, Prion disease, motor neurone diseases (MND), Huntington’s disease (HD), spinocerebellar ataxia (SCA), spinal muscular atrophy (SMA)
Three domains
For three research challenges

Scientific
- Animal models
- Biobanks
- Cohorts/registries
- Disease pathology

Medical
- Early diagnosis
- Prevention
- Clinical trials

Social
- Health care delivery
- Home automation
- Health economics
- Ethics
Governance

- **Management Board**
  - Decision-making Body, 1 voting member/country
  - One chair and one vice-chair
  - 26 member states and associated countries and one third party country
  - Chair Prof Philippe Amouyel (France)

- **Executive Board**
  - 5 members of MB
    - Vice-Chair Prof Adriana Maggi (Italy)
    - Enda Connolly (Ireland)
    - Edvard Beem (The Netherlands)
    - Mogens Horder (Denmark)
  - Prepare and implement MB decisions

- **Scientific Advisory Board**
  - 15 world-class scientists in the field of basic, clinical and social/healthcare ND research
  - Chair Prof Thomas Gasser (Germany)
Scale / Scope / Impact

• Each country benefits from
  • The foresight vision of the most advanced countries
  • Multinational organization and an independent review board

• “A la carte” process
  • Each country is totally free to invest or not on a defined topic according to their own national agenda

• Researchers compete at international level, thus stimulating significantly the quality of research

• National teams have access to larger amounts of funding within a multinational call

• Assessment of JPND impact is planned
### JPND Mapping Exercise 2011

<table>
<thead>
<tr>
<th></th>
<th>Number of projects</th>
<th>Full value (€ millions)</th>
<th>%</th>
<th>Per year (€ millions)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>2,244</td>
<td>1,620</td>
<td>-</td>
<td>370</td>
<td>-</td>
</tr>
<tr>
<td><strong>Major investment</strong></td>
<td>357</td>
<td>1,329</td>
<td>82</td>
<td>273</td>
<td>73.8</td>
</tr>
<tr>
<td><strong>Smaller projects</strong></td>
<td>1,887</td>
<td>291</td>
<td>18</td>
<td>97</td>
<td>26.2</td>
</tr>
<tr>
<td><strong>By research category</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic</td>
<td>1,538</td>
<td>1,361</td>
<td>84</td>
<td>301</td>
<td>81.2</td>
</tr>
<tr>
<td>Clinical</td>
<td>515</td>
<td>183</td>
<td>11.3</td>
<td>47</td>
<td>12.8</td>
</tr>
<tr>
<td>Health and social care</td>
<td>919</td>
<td>76</td>
<td>4.7</td>
<td>22</td>
<td>6</td>
</tr>
</tbody>
</table>
ND research spend by disease area (annualised)

- AD: 31.4%
- PD: 14.3%
- MND: 3%
- Prion: 5%
- SMA: 0.7%
- SCA: 0.2%
- HD: 3.7%
- ND general: 41.7%
JPND Research Strategy

• What is it?
  • A holistic ‘roadmap’ for future EU-wide activity and investment
    • Not a review of the field, not a list of calls for proposals
  • Launched Feb 7th, 2012
  • 5 research priorities, 9 enabling activities

• Delivery has taken into account
  • SAB recommendations
    • Outputs from 4 scientific/strategic workshops
  • National and European portfolios
    • Mapping exercise of National and European programmes
  • Broad consultation with stakeholder groups
    • Both Online and Offline
Scientific Priorities

- Origins of neurodegenerative disease
- Disease mechanisms and models
- Disease definitions and diagnosis
- Treatments and prevention
- Healthcare and social care
Enabling Activities

- Knowing our research capability
- Supportive infrastructure and platforms
- Working in partnership with industry
- Working with regulatory organisations
- International partnership beyond Europe
- Capacity building
- Education and Training
- Connection to policy makers
- Communication and outreach
Available on JPND Website

- [http://www.neurodegenerationresearch.eu](http://www.neurodegenerationresearch.eu)
- [http://www.jpnd.eu](http://www.jpnd.eu)

- Full Research Strategy
- Executive Summary in 14 Languages
- Reports summarising responses received from consultations
Implementation and test-case

- **Joint Translational Call 2011**
  - “Optimisation/Harmonisation of biomarkers and their use in clinical centers”
  - 21 countries including Canada; 16M€; 4 projects funded

- **Centres of Excellence Network in Neurodegeneration Research (CoEN)**
  - Initiative considered part of the JPND
  - 6 countries; 3.7M€

- **JPND supports the “JPIs TO CO-WORK” project**
  - “Refine and promote the adoption of European-level guidelines in the domain of the Framework conditions for JPI”

- **JPND contributes to EU2020 objectives**
  - employment, education, growth of EU’s GDP, and reduction of stigma, poverty and social exclusion

- **Established links with Horizon2020**
  - JPND participates in European Innovation Partnership on Active and Healthy Ageing
Implementation – 5 Steps

1) Create list of priorities from JPND Research Strategy proposals

2) Organise thematic working groups

3) Create list of opportunities suited for implementation

4) Organise specific task forces

5) Support implementation
7 Scientific Priorities, 2012-2014

1. Genetic, epigenetic & environmental risk factors
2. Animal models for the identification of mechanisms underlying ND
3. Cross-disease analysis of pathways
4. Preventive strategies
5. Evaluating healthcare policy, strategies and interventions
6. Systematic Review(s) of “pathways to care”
7. Palliative and end-of-life care
Action groups

To better determine transnational research needs and opportunities in specific scientific areas

- Longitudinal Cohort Studies (disease-based and population-based strands)
- Animal and Cell Models
- Assisted Living Technologies
- Engagement and Partnership with Industry
- Engagement and Partnership with the EC and International Co-operations.
- Linkage and Alignment of National Plans and Initiatives
- User and Public Involvement in ND Research.
Total commitment anticipated 2011-2014

- Pilot Joint Transnational Call 2011 = €15M
- CoEN program call 2011 = € 4M
- CoEN calls 2012-2014 = €12M
- Joint Transnational Call 2012
  - identification of genetic, epigenetic and environmental risk and protective factors” = €16M
  - evaluation of health care policy, strategies and interventions = € 8M
- Estimate commitment 2013 = €25M
- Estimate commitment 2014 = €25M

Total projected investment: over €100M in cash contribution (no in-kind resources included).
Keep up to date

- Visit the JPND website:
  - http://www.neurodegenerationresearch.eu
  - http://www.jpnd.eu

- Search our Mapping Database

- Sign up to the JPND News Feed

- Follow us on Twitter: @JPNDEurope

- E-mail us: secretariat@jpnd.eu
  philippe.amouyel@pasteur-lille.fr