Joint Programming in Neurodegenerative Disease Research (JPND)

Meeting the needs of patients, academia, and industry

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Vice-Chair, JPND Scientific Advisory Board

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We cannot tackle neurodegenerative diseases by acting as single countries.

JPND is a global research initiative led by EU countries, with 27 member states, associated countries and third countries participating.
JPND brings together......

- **Scientists**
  - Independent Scientific Advisory Board - 18 of the world’s top basic, clinical and healthcare research scientists in the ND area

- **Research Evidence**
  - JPND Mapping Database demonstrates the current scale and scope of ND research amongst JPND-participating countries
  - The greatest amount of funds available for ND research is through national government budgets:
    - **Total research funding:** 1.621 Billion
      - Basic research: 1.362 Billion
      - Clinical research: 183 Million
      - Healthcare/Social Research: 76 Million

- **National Research Funding bodies**
  - 27 countries participating in the JPND Management Board
  - each member mandated by their government to act and to commit funds
**JPND Mapping**

- **€1.62bn investment – 357 programmes, 1887 smaller projects**
- **238 bioresources captured**

<table>
<thead>
<tr>
<th>Survey Section</th>
<th>Entries</th>
<th>Which represents:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisational Details</td>
<td>75</td>
<td>Organisations from 21 countries</td>
</tr>
<tr>
<td>Smaller Investments</td>
<td>1887</td>
<td>€0.29 billion – 69 agencies from 21 countries + EC including ERC, covering 1756 projects</td>
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<tr>
<td>Major Programmes</td>
<td>357</td>
<td>€1.33 billion - 41 funding agencies (13 countries + EC - including ERC)</td>
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<tr>
<td>Research Networks</td>
<td>34</td>
<td>8 countries + Europe-wide</td>
</tr>
<tr>
<td>Population Cohorts</td>
<td>72</td>
<td>15 countries + Europe-wide</td>
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<tr>
<td>Case Control Studies</td>
<td>22</td>
<td>9 countries</td>
</tr>
<tr>
<td>Disease Registries</td>
<td>21</td>
<td>9 countries + Europe-wide</td>
</tr>
<tr>
<td>DNA, Tissue &amp; Cell line Banks</td>
<td>87</td>
<td>15 countries</td>
</tr>
<tr>
<td>Animal Model Repositories</td>
<td>12</td>
<td>8 countries</td>
</tr>
<tr>
<td>Bio/Neuro Infrastructures</td>
<td>24</td>
<td>8 countries + Europe-wide</td>
</tr>
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DEFRAGMENTATION – WHAT JPND IS ALL ABOUT

STRATEGIC RESEARCH AGENDA

ALIGNMENT OF EU COUNTRIES ON COMMON RESEARCH GOALS
Meeting needs of stakeholders

- **SRA Delivery took into account:**
  - SAB recommendations
    - Outputs from 4 scientific,strategic workshops
  - National and European portfolios
    - Mapping exercise of National/European programmes
  - Broad consultation with stakeholder groups
    - Both Online and Offline

- **Modification of Scientific Advisory Board**
  - Now includes scientists representing patient groups (2) and industry (2)

- **Ongoing communication + engagement of stakeholders**
Aligning research strategies

- Most JPND countries
  - No national roadmap
  - No identified priority actions in the field of ND research

- Those who do, take different approaches
  - Specific research programmes
  - National plans targeted to an individual disease (e.g. Dementia)
  - National plans comprising research, service delivery, or both

- Since deciding to participate in JPND…..
  - Denmark, Finland, Italy, Ireland working towards developing SRAs

- Specific JPND actions aimed at encouraging countries to develop national research strategies in ND
Aligning national activities

• JPND Action Group to align existing national resources and initiatives
  • to address specific ND research questions

• Focus on linkage, harmonization and data sharing between areas with high potential for international cooperation

• e.g. connecting national technology platforms or infrastructures
  • imaging centres
  • biobanking infrastructures
JPND Research

Basic

Clinical

Healthcare/Social

PARTNERSHIP

• 27 JPND Members
  • Member States
  • Assoc. Countries
  • Third Countries
• Eur. Commission
• Industry
• Public and Users

ACTIONS

• Common Strategy
• Transnational Calls
• Alignment Actions
• National Plans
• Communication + Dissemination

OUTCOMES

• New treatments + preventive strategies
• Improved health + social care approaches
• De-stigmatize ND
• Alleviate economic and social burden
What are the conditions that create an environment ripe for innovation?

- **Joint Transnational Calls**
  - One in 2011 for €16 M
    - Optimization of biomarkers and harmonization of their use
  - Two in 2012-2013 for €29 M
    - Risk Factors + Evaluation of Healthcare
  - Two in 2013-2014

- **Centres of Excellence in Neurodegeneration (CoEN)**
  - 2011 for €6 M
  - 2012-13 for €8 M – Pathfinder projects
Emerging national JPND-related activities

- **The Netherlands**
  - Research a major theme as part of National Deltaplan for Dementia
  
  “.... the Deltaplan will follow closely the JPND strategic research agenda and will strengthen the international position of the Netherlands for both research and industry”

  Edith Schippers, Minister for Health, Welfare and Sport

- **United Kingdom**
  - David Cameron’s “*Prime Minister’s challenge on dementia*” includes specific references to continued support for COEN and JPND research

- **Ireland**
  - National SRA developed to inform participation in JPND
  
  Researchers using participation in 2011 JPND Biomarkers call to initiate a national network in biomarkers for Alzheimer’s and Parkinson’s
Partnering with Industry

- Substantive participation in development of JPND Research Strategy
- Now Members of Scientific Advisory Board
- Ongoing discussions with EFPIA-IMI
- Expand the engagement to medical device, IT, diagnostics, imaging, welfare technologies, AAL, …)
- JPND Industry Action Group established to develop new public-private-partnerships
Alignment - Actions

- Action Groups have begun in priority areas:
  - Longitudinal Cohort Studies
    - addressing both disease-based and population-based cohorts
  - Animal and Cell Models
  - Assisted Living Technologies
  - Palliative Care
  - User and Public Involvement in Research
Changing the trajectory

**Proportion of American Age 65 and older with Alzheimer Disease by Stage of Disease 2010-2050**

2010 **Current Trajectory**
- Mild 28%
- Moderate 31%
- Severe 41%
- Total 5.1 Million

2050 **Current Trajectory**
- Mild 23%
- Moderate 29%
- Severe 48%
- Total 13.5 Million

2050 **Delayed Onset**
- Mild 25%
- Moderate 30%
- Severe 45%
- Total 7.7 Million

What if we delay the onset and progression?

Impact of a 5-year delay on the onset by stage of disease, Americans aged 65 and older with AD, 2050

Courtesy M. Di Luca 2013
CSF Aβ

PIB Binding

CSF Tau

Hippocampal Volume

Brain Metabolism

Episodic Memory

CDR-SB

Years

Estimated Age at Onset of Symptoms

Morris et al, 2012
FTLD Progranulin Mutation
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 Feeds

- E-mail us: secretariat@jpnd.eu

- Follow us on Twitter: @JPNDEurope