EU Joint Programme - Neurodegenerative Disease Research (JPND)

Coordinating approaches to research across Europe

Philippe Amouyel
JPND
22/11/2013
A global health and economic emergency

- Between now and 2050, over 680 million new cases of dementia will be diagnosed worldwide.¹

- That’s 680 million people living with dementia in the next 40 years!
  - more than the population of all of North America (542 million) and nearly as much as all of Europe (738 million)

- ND are the most expensive of all known diseases
  - Global cost of dementia in 2010 is $604 billion - 1% of global GDP.²

- Current economic crisis is affecting research budgets

¹ – World Alzheimer Report 2012
² – WHO Dementia Report 2012
A Global Challenge Requires Global Collaboration

A compartmentalised ERA

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

G. Clarotti - JP - 03-10
A compartmentalised ERA

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

EU27 + EC

G. Clarotti - JP - 03-10
A compartmentalised ERA

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

- Transnational Collaboration in EU 27: 10 to 15%
- Competitive Federal Funding in US: 85 to 90%

Mio Euro

EU27 + EC

G. Clarotti - JP - 03-10
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.
We cannot tackle neurodegenerative diseases by acting as single countries.

JPND is a global research initiative led by EU countries, with 27 participating EU Member states, Associated countries, and Third countries.

Increasing coordination of national research programmes to improve impact and effectiveness.
Organisation

Management Board
- 27 countries represented
- Members mandated to act
- Chair Philippe Amouyel - France

Executive Board
- Vice-Chair Adriana Maggi - Italy
- Rob Buckle - UK
- Mogens Horder – Denmark
- Marlies Dorloechter - Germany

Steering Committee
- Executive Board
  + Enda Connolly - Ireland
  + Edvard Beem - Netherlands

Scientific Advisory Board
- 18 Members, chosen for scientific excellence and competence

JPND currently partly-supported by FP7-JUMPAHEAD (GA. 260774)
French participation
DEFragmentation - What JPND is All About

Strategic Research Agenda

Alignment of EU Countries on Common Research Goals
Scope of the initiative

Focus on Three Domains

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

Medical
- Early diagnosis
- Prevention
- Clinical trials

Social
- Health care delivery
- Home automation
- Health economics
- Ethics
Available on JPND Website

- http://www.neurodegenerationresearch.eu
- http://www.jpnd.eu

- Full Research Strategy
- Executive Summary in 14 Languages
- Reports summarising responses received from consultations
JPND Actions to date

- Common European Strategy
- Phase I Implementation (2012-2014)
  - Annual Transnational Calls for Proposals
  - Alignment Actions
- National Plans and Strategies
- Communication + Dissemination
JPND Annual Calls for Proposals

Centres of Excellence in Neurodegeneration (CoEN)

- 7 participating countries
- First call (2011) for €6M – 8 Projects
- Second call (2012-13) for €8M – 5 “Pathfinder” projects
JPND-supported projects

**ALS-CarE**

A Programme for ALS Care In Europe

Amyotrophic Lateral Sclerosis (ALS) is a rapidly progressive fatal neurodegenerative disease that affects the input to the spine of life, and for which there is no known cure. The principal aim of management is to maintain quality of life and reduce the symptoms of the disease. This requires a multidisciplinary approach using best practice for symptom alleviation, including innovative approaches towards maintaining quality of life.

The purpose of ALS CarE is to use existing information drawn from carers, to set up a system of care that is available to people with ALS of the correct time, in the correct format as a cost effective resource. This will be achieved by collecting details of contact and core services across all stages of the disease. A healthcare economic analysis will help to identify the overall costs of disease management, provide models of increased efficiency that prevent and increase quality of life, and begin to develop novel health economic measurement tools for terminal neurodegenerative diseases.

The completed project will provide user-friendly best practice programmes for ALS that can be modified for management of related degenerative diseases of the nervous system.

**DEMENTIA**

**DEMENTIA** has established a large European and global collaboration between national surveillance units and dementia research centres, facilitating cooperation between neuropsychologists, neuropsychologists and neurologists.

Our goals are:
- To harmonize the protocols involved in patient documentation, biomarker sampling, storage, biomarker handling, analysis and data sharing.
- To standardize a more precise diagnosis in patients with rapidly progressive dementia by analysis of the biochemical markers in the cerebrospinal fluid and blood.
- To improve CSF-based diagnosis in dementia by application of new methodologies.

We work on the translation of in vivo and in vitro parameters that are related to cerebral function. As an added value, we will delineate criteria for early differential diagnosis between rapidly progressive neurodegenerative or potentially reversible dementias.

**RIMod-FTD**

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Early December 2013

CALLING ALL RESEARCHERS!!

2013 JPND Calls for Proposals

The EU Joint Programme - Neurodegenerative Disease Research (JPND) expects to launch two Joint Transnational Calls in December 2013 aimed at supporting collaborative research in the following areas:

- Cross-Disease Analysis of Pathways related to Neurodegenerative Diseases
- Pilot Studies for Preventive Strategies for Neurodegenerative Diseases
Online Partnering Tool

Welcome to the JPND Partnering Tool | About the tool

Looking for partners for your project?
With the JPND partner finder, it is easy to register your research group’s experience, and get an overview of other registered groups.

- Register research group
- Search for partners

Have a proposal idea for a JPND call?
Registering a proposal idea for a JPND call is the first step towards drafting a proposal online using this tool. Once your idea is registered, you can choose to make it visible to all users to gain interest and feedback, or you can form private consortia around it, inviting selected partners to join, potentially leading to the drafting of a proposal.

To register a proposal idea, click on the relevant button below:

- Cross-Disease Analysis of Pathways
- Preventive Strategies

Browse research groups

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<td>JPND-1328</td>
<td>Example of a Preventive Proposal</td>
<td>10/31/2013</td>
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Online Partnering Tool

Register Research Group

Create Personal Profile
Online Partnering Tool

Register proposal Idea and form consortia online
Alignment Actions

- Action Groups have begun in priority areas:
  - Longitudinal Cohort Studies
  - Animal and Cell Models
  - Assisted Living Technologies
  - Palliative Care
  - Patient and Public Involvement in Research
Keep up to date

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

- Register on the Partnering Tool

- Sign up to the JPND News Feeds

- E-mail us: secretariat@jpnd.eu

- Follow us on Twitter:

  @JPNDEurope