

# Joint Programming in Neurodegenerative Disease Research (JPND)

*Coordinating approaches to research across Europe*

**Adriana Maggi, JPND Vice-chair**  
**Dementia Conference**  
**Rome 14/11/2014**

# DEMENTIA

## A global health and economic emergency

- Between now and 2050, over 680 million new cases of dementia will be diagnosed <sup>1</sup>
- Global cost of dementia in 2010 is \$604 billion<sup>2</sup>

1 – World Alzheimer Report 2012

2 – WHO Dementia Report 2012




# What is Joint Programming in Research?

**Close to 85% of public research funds in the EU  
are spent independently by Member States**

- Countries working together
  - to identify the core research questions (or the next societal challenge)
  - to define, develop and implement a common research agenda
  - to defragment, avoid duplication and synergize on common research themes
- Implementation of the SRA through voluntarily, a-la-carte, variable geometry activities





**We cannot tackle neurodegenerative diseases by acting as single countries**

**JPND is the largest global ND research initiative led by EU countries, with 28 participating**

**EU member states**

**Associated countries**

**Third countries**

**Increasing coordination of national research programmes to improve impact and effectiveness**

**Albania**  
**Austria**  
**Belgium**  
**Canada**  
**Croatia**  
**Czech Republic**  
**Denmark**  
**Finland**  
**France**  
**Germany**  
**Greece**  
**Hungary**  
**Ireland**  
**Israel**  
**Italy**  
**Luxembourg**  
**Netherlands**  
**Norway**  
**Poland**  
**Portugal**  
**Romania**  
**Slovakia**  
**Slovenia**  
**Spain**  
**Sweden**  
**Switzerland**  
**Turkey**  
**United Kingdom**

# JPND brings together

- Researchers (Basic, Clinical, Healthcare/Social)
- National Funding Bodies
- National Research Strategies and Investments



# Organisation

## Management Board

- 28 countries represented
- Members mandated to act
- Chair Philippe Amouyel - France

## Executive Board

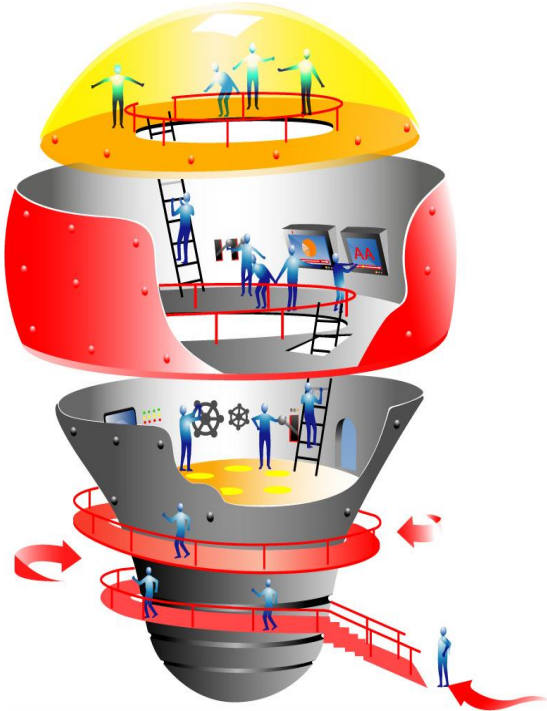
- Vice-Chair Adriana Maggi - Italy
- Robin Buckle - UK
- Mogens Horder - Denmark
- Marlies Dorlochter - Germany

## Steering Committee

- Executive Board +
- Rainer Girgenrath - Germany
  - Edvard Beem - Netherlands

## Scientific Advisory Board

- 18 Members, chosen for scientific excellence
- Industry and Patient Organisations represented





# Defragmentation

## – what JPND is all about...



### STRATEGIC RESEARCH AGENDA



### ALIGNMENT OF EU COUNTRIES ON COMMON RESEARCH GOALS



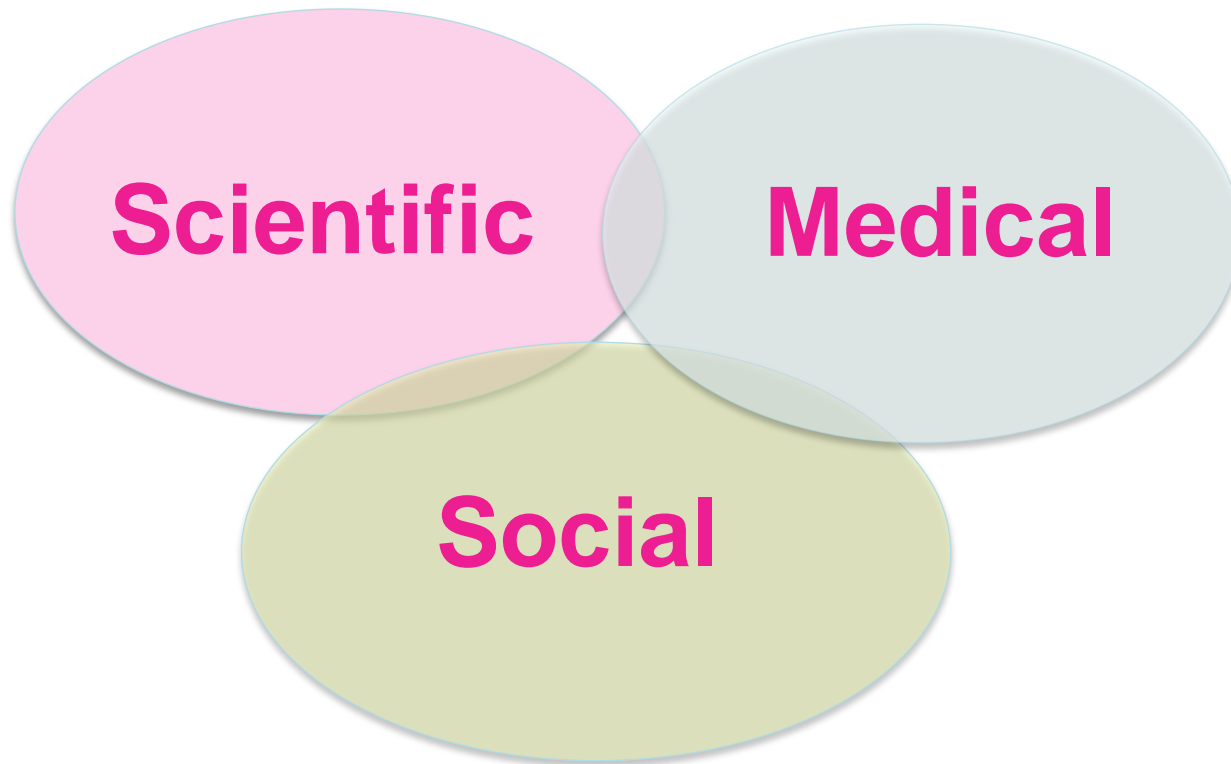
# JPND Research Strategy (SRA)

- **Agreed by all JPND Member States + Assoc. Countries**
  - Officially Launched Feb 7<sup>th</sup> 2012
- **Thematic priorities for future research:**
  - The origins of neurodegenerative disease
  - Disease mechanisms and models
  - Disease definitions and diagnosis
  - Developing therapies, preventive strategies and interventions
  - Healthcare and social care





# Scope of JPND Research



# Neurodegenerative Diseases?

- **The neurodegenerative diseases that JPND focuses on are:**
  - Alzheimer's disease (AD) and other dementias
  - 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)



# JPND Research Strategy (SRA)

- **SRA Enabling Activities:**
  - JPND will deliver the SRA within the next ten years through a combination of:
    - Knowing our research capability
    - Opportunities for infrastructure and platforms
    - Working in partnership with industry
    - Working with the regulators
    - Global partnership
    - Capacity building
    - Education and training
    - Connection to policy makers
    - Communication and outreach



# JPND Action Groups

➤ Alignment of National Strategies

➤ Alignment of National Activities

➤ Longitudinal Cohorts

➤ Assisted Living Technologies

➤ Industry Partnership

➤ Animal and Cell Models

➤ Palliative Care

➤ Patient + Public Involvement

➤ Optimisation of biomarkers



# Action Group Recommendations



# “Rapid Action” Call for working groups

26

Aug,  
2014

## Results from 2014 JPND “Rapid Action” Call for Working Groups on Longitudinal Cohort studies

### Ten international working groups to be funded under JPND call

The EU Joint Programme Neurodegenerative Disease Research (JPND) has released the results of a “rapid action” call to support ten groups of leading scientists in finding ways to enhance the use of longitudinal cohort studies for neurodegenerative disease (ND) research.

JPND launched this call on 23rd April 2014 as part of a series of new JPND initiatives, designed to amplify the impact of research by aligning and building upon existing national programmes and initiatives, and to bring a more wide-ranging and multidisciplinary approach to research on neurodegenerative diseases.

The awarded proposals are for top ND scientists to come together and recommend how to address the most pressing issues that prevent full use of longitudinal cohorts. This includes population studies and disease cohorts, both having considerable potential for ND research. Funding decisions were based upon scientific evaluation and



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## Coordination and development of best practice

### 10 JPND working groups to address methodological challenges for longitudinal cohort studies such as:

- Cognition / Functional assessment
- Biomarkers
- Biobanking
- Imaging
- Health and social outcomes
- Presymptomatic ND



# SRA Implementation (2012-2014)

## Annual Calls for Proposals

Year	Total fund available	Research Area	No. of Projects
2011 (pilot)	€16M	Optimization of biomarkers + harmonization of their use	4
2012	€18M	Risk and Protective Factors	5
2012	€11M	Evaluation of Healthcare	6
2013	€12M	Cross-Disease Analysis	10
2013	€11M	Pilot Preventive Strategies	5

## Centres of Excellence in Neurodegeneration (CoEN)

2011	€6M	Phase I : common resources and methodological approaches	8
2012-13	€8M	Phase II : “Pathfinder” projects	5

# Call statistics

Year	Call area of interest	No. of proposals submitted	Budget requested (million €)	No. of proposals recommended for funding	No. of proposals supported	Budget supported (million €)	Success rate (%)
2011	Harmonization of Biomarkers	14	€31	5	4	€14	29%
2012	Risk and Protective Factors	52	€97	18	5	€17	10%
2012	Healthcare Evaluation	22	€29	9	6	€9	27%
2013	Cross-Disease Analysis	90*	€112	23	10	€12.5	11%
2013	Pilot Preventive Strategies	35*	€36	5	5	€7	14%
<b>Total</b>		<b>213</b>	<b>€157m</b>	<b>60</b>	<b>30</b>	<b>€59.5m</b>	<b>18%</b>

\* pre-proposals



# JPND-supported projects in Risk and Protective Factors

- **APGeM:**  
Pre-clinical genotype-phenotype predictors of Alzheimer's disease and other dementia  
Coordinator: Tormod Fladby, Akershus University Hospital and University of Oslo, Norway
- **COURAGE-PD:**  
COMprehensive Unbiased Risk factor Assessment for Genetics and Environment in Parkinson's Disease  
Coordinator: Thomas Gasser, University of Tübingen, Germany
- **PERADES:**  
Defining Genetic, Polygenic and Environmental Risk for Alzheimer's Disease using multiple powerful cohorts, focussed Epigenetics and Stem cell metabolomics  
Coordinator: Julie Williams, Cardiff University, United Kingdom
- **RiMod-FTD:**  
Risk and Modifying factors in Fronto Temporal Dementia  
Coordinator: Peter Heutink, German Center for Neurodegenerative Diseases – Tübingen, Germany
- **STRENGTH:**  
Survival, Trigger and Risk, Epigenetic, eNvironmental and Genetic Targets for motor neuron Health  
Coordinator: Ammar Al-Chalabi, King's College London, United Kingdom



- **EURO-SCD:**

- **MIND-AD:**

- **NEUROEXERCISE:**

- ONWebDUALS:

- **PreFrontAls:**

**JPND**  
research  
European Commission

**RIMod-FTD**  
Risk and Modifying factors in Fronto-Temporal Dementia

Fronto-Temporal Dementia (FTD) is a devastating neurological *only rarely* dementia with a strong genetic influence. Currently, seven genes have been identified but explain 50% of familial cases, but how these different genetic factors lead to a very similar clinical phenotype is still an unresolved question.

Currently, there is no cure for FTD and the development of successful therapies is essential to understand the role of genetic and environmental risk factors in the disease process and which therapeutic factors are required in the progression of the disease in all patients and which are specific for subgroups of patients. We therefore aim to investigate common and disease affected processes in selected groups of FTD patients using a combination of genetic and cell biological approaches on basis of selected patient groups and corresponding animal and cell model systems. Our long-term approach is focused and necessary for successful therapy development because it allows an unbiased selection of the most suitable target for the disease process and the most suitable targets to modify the disease phenotype and thus provide better choices for therapy development.

**Total Funding:** To be finalised\*

**Start Date:** January 2014

**Duration:** 3 years

**Coordinator:** Peter Heutskamp

**RIMod-FTD**

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**Project Partners:**

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- Peter Heutskamp** University College London, United Kingdom
- Anna Breda** University College London, United Kingdom
- John van den Bogaard** and **John van der Ven** University of Amsterdam, The Netherlands
- Philippe Legrand** Université de Reims, Reims, France
- Philip van Damme** Ghent University Hospital – Ghent, Belgium
- John Sleat** Copenhagen University Denmark
- Anna Breda** Center Center for Neurodegenerative Diseases – Göttingen, Germany
- John van den Bogaard** and **John van der Ven** University of Amsterdam, The Netherlands
- Richard Breda** Center Center for Neurodegenerative Diseases – Bonn, Germany

# JPND-supported projects

## • Cross Disease Analysis

### • CeBioN:

Cellular Bioenergetics in Neurodegenerative Diseases: A system-based pathway and target analysis

Coordinator: Maria Ankarcrona, Sweden

### • CrossSeeds:

Mechanisms of pathogenic protein cross-seeding in neurodegenerative disorders

Coordinator: Hans-Ulrich Demuth, Germany

### • DAMNDPATHS:

Elucidation of common transcriptional targets in vulnerable Dopamine, Motor Neuron and frontotemporal Dementia disease PATHwayS

Coordinator: Eva Hedlund, Sweden

### • Fly-SMALS:

Common RNA-dependent pathways for motor-neuron degeneration in spinocerebellar muscular atrophy and amyotrophic lateral sclerosis

Coordinator: Jörg B. Schulz, Germany

### • InCure:

Innate Immune Activation in Neurodegenerative Disease

Coordinator: Michael T. Heneka, Germany

PROJECTS SUPPORTED BY JPND



**RiMod-FTD**  
Risk and Modifying factors in Fronto-Temporal Dementia

Fronto-Temporal Dementia (FTD) is a devastating progressive early onset dementia with a strong genetic influence. Currently, seven genes have been identified that explain 50% of familial cases, but how these different genes lead to a very distinct clinical phenotype is still an unsolved question. Currently, there is no cure for FTD and for the development of successful therapies it is essential to understand the role of all genetic and environmental risk factors in the disease process and to investigate which factors are involved in the progression of the disease in all patients and which are specific for subgroups of patients. We therefore aim to investigate common and differently affected processes in different groups of FTD patients using a combination of genomic and cell biological approaches on basis of selected patient groups and corresponding animal and cellular model systems. Our integrative approach is novel and necessary for successful therapy development because it allows an unbiased selection of the most suitable targets that can improve our understanding of disease process and in addition will help identify the key genes in the disease process that are the most suitable targets to modify the disease phenotype and thus provide better choices for therapy development.

**Total Funding:** To Be Finalized\*  
**Start Date:** January 2014  
**Duration:** 3 years  
**Coordinator:** Peter Heutzel  
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**Project Partners:**

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- Patrick Langen**, BrainScale Europe, Antwerp, Belgium
- Philip van Daele**, Vrije Universiteit Brussel, Brussels, Belgium
- John Hardy**, University of Edinburgh, Edinburgh, Scotland
- Andreas Bredt**, German Center for Neurodegenerative Diseases, Göttingen, Germany
- Stefan Leisenberger**, Technical University Munich, Germany
- Richard Woodhouse**, German Center for Neurodegenerative Diseases, Bonn, Germany

\*Contributors from participating JPND Member Countries are currently being invited to the project



## JPND-supported projects

- **Cross Disease Analysis (cont'd)**

- **MisingLink:**

Identification and structural characterization of the primordial cytotoxic conformers of the amyloidogenic cascade: Ideal prevention/diagnostic/therapeutic targets in neurodegeneration

Coordinator: Mariano Carrión-Vázquez, Spain

- **NeuroGeM:**

## Identification of genes that modulate the severity of all neurodegenerative diseases

Coordinator: Jörg Gsponer, Canada

- **NeuTARGETs:**

# Targeting the propagation of pathogenic protein assemblies in neurodegenerative disease

Coordinator: Chiara Zurzolo, France

- **PrPC&PDK1:** The PrPC / PDK1 / TACE signaling axis at the cross-road of several aggregate-prone protein-associated neurodegenerative diseases **Coordinator:** Benoit Schneider, France

- **SynSpread:**

## Role and mechanism of alpha-synuclein and ataxin-3 spreading in Parkinson and Machado-Joseph diseases

Coordinator: Luis Pereira de Almeida, Portugal

**JPND**  
research  
European Union's Joint Programme  
Neurodegenerative Disease Research

**RIMod-FTD**  
Risk and Modifying factors in Fronto-Temporal Dementia

Fronto-Temporal Dementia (FTD) is a devastating progressive neurodegenerative disorder with a strong genetic influence. Currently, even genes have been identified that explain 50% of familial cases, but there are three different genetic pathways to a similar clinical presentation, all still an unexplained puzzle.

Currently, there is no cure for FTD and for the development of successful therapies it is essential to understand the role of all genetic and environmental risk factors in disease process and to investigate whether genes are important in the progression of the disease in all patients and which are specific for subtypes of patients. We therefore aim to investigate common and differently affected pathways in different groups of FTD patients using a combination of genomic and cell biological approaches on tissues of affected patient groups and corresponding control and on cellular model systems. Our integrative approach is novel and necessary for successful therapy development because it covers an unbiased selection of the most suitable targets that can improve our understanding of disease process and establish a rational basis for drug development. The disease process that are the most suitable targets to modify the disease phenotype and therefore provide choices for therapy development.

**Total Funding:** to be finalized\*

**Start Date:** January 2014

**Duration:** 3 years

**Coordinator:** Peter Heutloff

**RIMod-FTD**

**EU Project Number:** FP7-260132

**EU Project Website:** [rimod-ftd.eu](http://rimod-ftd.eu)

**Project Partners:**

- Austria:** Center for Neurodegenerative Diseases – Göttingen, Germany
- Belgium:** University College London, United Kingdom
- Denmark:** University of Copenhagen, Denmark
- France:** Centre National de la Recherche Scientifique, France
- Germany:** Charité – Universitätsmedizin Berlin, Germany
- Greece:** University of Athens, Greece
- Italy:** University of Turin, Italy
- Japan:** University of Tokyo, Japan
- Netherlands:** University of Amsterdam, Netherlands
- Poland:** Jagiellońska University, Poland
- Portugal:** University of Coimbra, Portugal
- Romania:** University of Medicine and Pharmacy, Bucharest, Romania
- Spain:** University of Valencia, Spain
- Sweden:** University of Gothenburg, Sweden
- Switzerland:** University of Zurich, Switzerland
- United Kingdom:** University of Cambridge, United Kingdom
- United States:** University of California, San Francisco, USA

\* Contributions from participating JPHS Member Countries are currently being finalized for this project.

# Partnership with the EC

- Establish programme of co-investment to leverage the value of investments and resources at both national and EC level, to the benefit of Europe
- **Synergy between JPND actions and H2020 programme**
  - First call of Horizon 2020 (Dec. 2013)
  - ERA-NET cofund: Implementing a transnational call with EU co-funding
- **Three Call Topics in preparation for the end 2014/beginning 2015:**
  - Identification of genetic, epigenetic and environmental risk + protective factors
  - Longitudinal cohorts in ND research
  - Advanced experimental models of ND



# Pre-call announcement

JPND is the largest global research initiative  
aimed at tackling the challenge of neurodegenerative diseases

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## NEWS & MEDIA

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05

Nov,  
2014

## Joint Transnational Call for Research Proposals – Preannouncement

The EU Joint Programme – Neurodegenerative Disease Research (JPND) will shortly begin a major new cohesive action with the European Commission – the first concrete synergy between JPND and Horizon 2020 designed to address the global threat of neurodegenerative diseases.

As part of this new initiative, **JPND will launch a joint transnational call for proposals in January 2015** aimed at supporting transnational research collaborations in three JPND priority areas:

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