

## Impact Outlook

- ‘The Joint Programming Initiative aims to address “grand challenges” to the EU and global society by coordinating national research programmes to increase the impact and effectiveness of research efforts’
- ‘Through JPco-fuND there has been a significant scale-up in the implementation of the JPND research strategy, and a major step forward in terms of tackling more efficiently the global challenge of neurodegenerative disease’

# Standing ground against one of the greatest global challenges

*With predictions to the tune of 132 million people set to be living with dementia by 2050, the EU Joint Programme – Neurodegenerative Disease Research has a tall order ahead of it, however through collaboration it has every chance of success*

### Could you firstly explain a little about the neurodegenerative diseases the JPND is predominantly concerned with and the scale of the problem?

Neurodegenerative diseases such as Alzheimer’s disease and Parkinson’s disease are one of the greatest challenges the world faces this century. One new case of neurodegenerative disease, most commonly dementia, appears every three seconds in the world. Yet, with the exception of a few cases, no curative treatment exists.

It’s a challenge that will only grow. Take the case of dementia: according to Alzheimer’s Disease International, an estimated 47 million people are currently living with dementia. This number is expected to almost double every 20 years, and by 2050 some 132 million people will be living with dementia. Between now and 2050, over 680 million new cases of dementia will be diagnosed worldwide. That’s 680 million people living with dementia in the next 35 years. This creates a heavy burden on the individuals with the disease, as well as their relatives and society as a whole. Indeed, dementia is among the world’s most expensive diseases: In 2015, the worldwide cost of dementia was \$818 billion – equivalent to 1.09 per cent of global GDP – and by 2030 it is expected to climb to \$2 trillion.

### What is the background of the JPND?

The Joint Programming Initiative aims to address “grand challenges” to the EU and global society by coordinating national research programmes to increase the impact and effectiveness of research efforts. Neurodegenerative diseases represent one of the world’s most pressing medical and societal challenges, and the solutions are likely beyond the scope and resources of any single country; we can only confront this common challenge by maximising our collective potential at European and global levels.

As the initial pilot of these Joint Programming Initiatives, JPND enables participating countries to collaborate on the challenge of age-related neurodegenerative diseases on a voluntary basis and to defragment research funding within countries for increased efficiency. This means they can participate according to their national priorities and areas of excellence. JPND aims to use this Joint Programming approach of efficient and goal-oriented research collaboration to optimise national research strategies and funding schemes in order to reach its ultimate goal: finding causes, developing cures and identifying better ways of caring for people with neurodegenerative diseases.

The first step in accelerating discoveries in basic science is to increase the number of scientists and physicians working together in a given field and to offer them large amounts of funding for their research. This is what JPND does by supporting highly competitive transnational collaborative projects that link research teams from several countries and by juxtaposing large national research grants, creating a virtual common pot that simply and efficiently supports each team for a common goal.

Moreover, it is possible to reduce the delay from bench to bedside by enhancing the relationship between public and private research, especially by supporting translational research. Neurodegenerative disease research is not limited to finding curative treatments; these chronic diseases also require other forms of support, both for the patients and the caregivers. For this reason, JPND also strongly supports social and healthcare research, as well as public and patient involvement.

Although JPND was originally a European initiative, it has since gone global, with 30 countries now participating.

### Can you give an example of a JPND-supported project that has made significant headway in the battle against neurodegenerative diseases?

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In 2011, JPND launched its very first call, dedicated to projects focused on the optimisation of biomarkers and the harmonisation of their use between clinical centres, a key topic in the improvement of diagnoses in both basic and clinical research. One project selected for support was BIOMARKAPD, an initiative aimed at standardising sampling and measurement for biomarkers across most centres in Europe. Bringing together 52 partners from 21 countries, BIOMARKAPD was a major success, resulting in more than 135 publications in peer-reviewed journals and the identification of two new biomarkers. The project, which ran from 2012-2015, also enabled additional laboratory training and certification among project partners. The members of BIOMARKAPD have opted to continue their work as the CSF Society, an initiative they established independently at the end of the project.

#### Could you talk a little about the creation of the Strategic Research and Innovation Agenda (SRIA)?

A Joint Programming Initiative is based on three main pillars: a strategic vision, a common research and innovation agenda and an efficient management structure. One key element of JPND is its common research strategy, which sets out the common vision of the JPND countries involved. It provides a strategic approach to supporting world-class research that can exploit emerging scientific opportunities, confront barriers to progress and provide new approaches to prevention, intervention and care.

Our strategy is based on the recommendations of the JPND Scientific Advisory Board, which constitutes 15 of the very best scientists and physicians from the research areas related to neurodegenerative diseases. Extensive consultations with over 140 scientists and the multiple stakeholder communities of JPND were also conducted, and recommendations were validated through a broad public consultation. To promote public involvement in research in order to improve the way that neurodegenerative disease research is prioritised, commissioned, undertaken, communicated and used, a JPND Patient and Public Involvement (PPI) Stakeholder Advisory Board was established in 2014. The primary aim of the Board is to provide rapid and frank feedback and early advice from the broad PPI stakeholder community to JPND in relation to the implementation of PPI in neurodegenerative disease research.

#### Could you explain how useful the JPND's mapping exercise has been and any plans for a follow-up exercise?

JPND's mapping exercise provided an in-depth and objective analysis of current research activity and resources related to ND. The exercise had two main goals. First, we wanted to ensure the existing research landscape was fully understood and taken into account in the shaping of our research strategy. The second objective was to provide a usable and useful resource for the research community. Our hope was that the availability of a freely accessible and searchable web-based database, containing detailed information on funded research, resources and infrastructures, would encourage networking, collaboration and

resource sharing. It also has the potential to help bring new researchers to the field.

#### Could you offer more information about the JPco-fuND initiative?

In 2014, JPND and the European Commission launched a major new cohesive action called 'JPco-fuND.' This initiative proposed a five-year work programme including the launch of an EU co-funded joint transnational call for research proposals in January 2015. This call was aimed at supporting international research collaborations in three JPND priority areas: Longitudinal Cohorts, Animal and Cell Models, and Risk and Protective Factors.

At JPND, our funding rules are based on excellence. Thus we support research projects only if they have been selected by an international and independent common review board that delivers a ranking list strictly followed by the JPND management board. Our ability to fund projects according to this ranking list is tightly linked to the earmarked budget anticipated by the participating countries in the virtual common pot. However, the earmarked budget of one country may not be sufficient to cover all of its successful teams and thus may block the advancement of a project on the ranking list if not adequately increased. Therefore, the ability of the Commission to fund any European country may help solve this issue, and the creation of the ERA-NET Cofund tools in Horizon 2020 constitutes a great opportunity. The 2015 JPco-fuND call is evidence of this: the ERA-NET Cofund raised 10 million euros and allowed for highly-efficient budget bridging. According to the ranking list of this call, without the EC JPco-fuND partnership and the very constructive discussion of the funding agencies who accepted to adjust their initial earmarked budget as efficiently as possible, we would have been able to fund only 10 projects. Thanks to JPco-fuND, we were able to recommend 21 world-class proposals for funding – projects that are now underway.

This was a significant scale-up in the implementation of the JPND research strategy, and a major step forward in terms of tackling more efficiently the global challenge of neurodegenerative disease.

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