

FOLLOWING AN INITIAL INTERVIEW IN MARCH 2013, **PROFESSOR JPND CHAIR PHILIPPE AMOUYEL** SPEAKS AGAIN TO **PEN** ABOUT HOW THE PROGRAMME HAS EVOLVED AND THE CHALLENGES THAT LIE AHEAD

## The need for neurodegenerative research

**E**urope has a rapidly ageing population. Currently, 16% of the European population is over 65, and this figure is expected to reach 25% by 2030. Neurodegenerative diseases such as Alzheimer's and Parkinson's are debilitating and largely untreatable conditions that are strongly linked with age.

It currently costs approximately €130bn per annum to care for people with dementia across Europe, highlighting age-related neurodegenerative disease as one of the leading medical and societal challenges faced by EU society.

Designed to tackle the challenge of neurodegenerative diseases, JPND aims to increase co-ordinate investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases.

Speaking again to Pan European Networks, the programme's chair, Professor Philippe Amouyel, outlines the advances that JPND has made as it has evolved, and where the future challenges now lie.

### What progress has been made in JPND in the last 12 months?

JPND is a global initiative, led by EU member states and has been operating for just over five years. As of today, 28 countries participate in JPND including 21 EU member states, five associated countries and two third countries (Canada and Switzerland). Tremendous progress has been made by JPND in that time in terms of increasing co-ordination, collaboration and alignment between national research programmes related to neurodegenerative disease research. This has resulted in an unprecedented mobilisation of awareness, human resources, actions, contributions and funding to tackle this problem which no country can address alone.

The past 12 months has seen JPND countries work together very effectively in a number of priority areas with activities moving forward in parallel, creating the necessary trust and alignment between the 28 participating countries in order to implement our Strategic Research Agenda (SRA). Guided by our Phase One Implementation Plan (2012-2014), these actions include, but are not limited to:

- Annual calls for proposals – two calls closed in February this year in the areas of 'preventive strategies' and 'cross-disease analysis of pathways', the final results of which will be announced in Autumn 2014;
- Alignment actions to determine research needs and opportunities in areas such as longitudinal cohort studies, animal and cell models and assisted living technologies;



Professor JPND Chair  
Philippe Amouyel

- Action groups to promote engagement and partnership, including with the European Commission and other international organisations.

These JPND actions, amongst others, are bringing together leading scientific experts and funding bodies to investigate the key research questions and barriers to progress in these areas. It is likely that further actions (including calls for proposals) will be developed and launched during this phase, with more than €100m in total due to be made available. Importantly, this funding will be in addition to, not instead of, other neurodegenerative disease funding.

It is important to note that JPND is moving beyond just calls for research proposals. Priority areas such as longitudinal cohort studies and animal and cell models have been assessed through expert-led JPND action groups and their recommendations are being adopted by JPND. For example, a 'rapid action' related to longitudinal cohorts is being launched in April 2014. This call is a JPND action to establish a series of community-led working groups to establish 'best practice' guidelines and methodological frameworks to overcome barriers to research in population studies and neurodegenerative disease related cohorts. This call is supported by nine JPND member countries (with others considering involvement) and currently has a budget of €450,000.

We are also moving towards realising another JPND medium-term objective: the development of cross-border transfer of funds. In order to do this, common procedures between JPND member countries need to be established and/or develop a common 'pot' that could centralise the funding. This issue is central to the joint programming concept, and partnership with industry and the European Commission is vital to address this issue. We are actively pursuing collaborative actions with the European Commission in this regard.



### Can you give us some other examples of JPND achievements?

One of the most advanced actions we have is in the area of animal and cell models. A serious limitation of modern neuroscience is the frequent failure to translate information from preclinical research into new treatments, diagnostics and preventive strategies. This limitation is particularly critical in the field of neurodegenerative diseases where, although studies conducted in experimental models provide invaluable physio-pathological information, they do not point to a clear therapeutic pathway.

The aim of this action group is to open up a discussion on the models currently available for ND research, and to devise strategies to overcome the current hiatus between the need to better understand the pathogenic mechanisms involved and the necessity to translate findings into diagnostic and therapeutic means.

Through the workings of the group, the most active European scientists in the field have joined forces to design a call for proposals which should stimulate more creative, multidisciplinary approaches for new experimental models which could identify markers of early prognosis and screen for potential therapeutic compounds. We are also aiming to support the organisation of

**The past 12 months has seen JPND countries work together very effectively in a number of priority areas with activities moving forward in parallel**

interactive online workshops on experimental models for the study of neurodegeneration.

Since JPND began, several member countries are now processing strategic research agendas for neurodegenerative diseases (e.g. Denmark, Portugal). These national research strategies will both inform their country's participation in JPND and will focus resources on tackling neurodegenerative diseases nationally, aligning with the European Research Strategy. Several new, related strategies (such as the Dutch Deltaplan for Dementia, and the UK Prime Minister's Challenge on Dementia) have also made specific references to JPND and are seen as the national vehicles for participation in JPND.

JPND is also engaging in strategic partnerships both nationally and internationally, focusing on areas where expertise can be pooled and more progress can be made through collaborative efforts. JPND was repeatedly highlighted at the G8 Dementia Summit in London last December as an example of successful international co-operation in dementia research, and we are now working with the new global plans and initiatives emerging from the summit.

As previously mentioned, JPND is also actively pursuing a partnership with the European Commission, while a meeting was also organised with the Office of Science and Technology Policy at the White House regarding future partnership with the USA. In addition, partnerships with industry, research funding agencies, and patient/carer organisations are being pursued in order to implement the JPND strategy in full.

The most important question for JPND in 2014 is how it is going to sustain the progress already being made. Our initial support from the European Commission ends later this year, so we are now preparing the sustainable management structure which will see JPND successes in



transnational collaboration in neurodegenerative diseases continue into the long term in order to tackle these chronic and complex diseases.

### **What new projects are currently being supported by JPND?**

A total of 11 new international research projects began in early 2014, supported under the JPND calls for European research projects for the “identification of genetic, epigenetic and environmental risk and protective factors” and “the evaluation of healthcare policies, strategies and interventions.” These projects, containing participants from 17 different countries, span areas such as risk factor assessment for genetics and environment in Parkinson’s Disease; preclinical genotype-phenotype predictors of Alzheimer’s disease and other dementias; a programme for ALS care in Europe; research to access policies and strategies for dementia in the young.

A good example is the PERADES project co-ordinated by Professor Julie Williams of Cardiff University, Wales, UK. This €6m project aims to explore the combined influence of genetics and lifestyle in the development of Alzheimer’s in one million people. User-friendly fact sheets on all of these projects are available on the JPND website.

In addition, the Network of Centres of Excellence in Neurodegeneration (CoEN) initiative is funding five new, innovative, ‘pathfinder’ projects, under its second funding call. CoEN is aligned with JPND, although it operates as an independent entity. Under CoEN, €3m has been awarded for five innovative and creative proof-of-principle studies which, if successful, will provide a step change in neurodegeneration research. The awarded projects take a ‘high risk, high pay-off’ approach to identify and validate new potential drugs and develop innovative therapeutic approaches for Parkinson’s disease, Alzheimer’s disease and other dementias.

**JPND can make significant impact, based on realistic targets. We can build capacity in basic, clinical and healthcare/social research. We can improve health and social care approaches**

### **Where will your priorities now lie?**

In the long term, we want to realise the ambitious JPND research goals: slow the progression, delay the onset, develop care approaches and ultimately prevent these diseases. We are working towards realising these goals within the next ten years. On the other hand, we have to balance that with scientific credibility – we are not going to cure these diseases in the next ten years.

JPND can make significant impact, based on realistic targets. We can build capacity in basic, clinical and healthcare/social research. We can improve health and social care approaches. We can translate research evidence into clinical, social and public health practice. We can alleviate the economic and social burden of these disorders. These actions are required together and in parallel in order to achieve the highest impact for the patients, their carers and for society as a whole in the coming years.

**Professor Philippe Amouyel**  
**Chair of the Management Board**  
**EU Joint Programme in Neurodegenerative**  
**Disease Research (JPND)**

**browse**  
[www.neurodegenerationresearch.eu](http://www.neurodegenerationresearch.eu)