


DEFEATING PUBLICATION  
**DEFEATING DUPLICATION**

*Professor Philippe Amouyel*

Chair, EU Joint Programme – Neurodegenerative Disease Research



JPND's core aim is to curb fragmentation in neurodegenerative disease research in Europe. However, Amouyel emphasises that this is a global problem requiring collaboration at the international level. He also discusses the balancing act required to ensure adequate investment in both cure and care

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**Can you remind us of The EU Joint Programme – Neurodegenerative Disease Research (JPND)'s core objectives and expand on its vision to tackle the challenge of neurodegenerative diseases?**

JPND is the largest global research initiative with the objective of tackling the challenge of neurodegenerative disease. Twenty-eight countries are participating in this European led initiative, made up of Member States, associated countries and other non-European countries, like Canada.

The goals are simple but accomplishing them is complex. They are to find the causes of neurodegenerative disease, find new treatments, develop cures and identify appropriate ways to care for patients. This is important because, for now, we don't have treatments that can cure the disease so we need to find ways to help people and alleviate the burden on their families.

The idea is to work jointly on this challenge and to avoid duplication of research efforts, which is what happens when you have separate programmes in different countries. If we work together at the European level and group all the funding we can work more efficiently and with greater investment. This is really the idea of JPND – to try to defragment. To do this there are three major requirements: that all the countries participating share a common vision, that a common strategic research agenda is built from this vision and that a simple management structure is put in place to implement our goals.

**Could you outline the extent of the current problem of neurodegenerative disease? What is the economic and social impact in Europe?**

A major characteristic of neurodegenerative disease is that it is tied to the age of the population. Europe and most developed countries have a rapidly ageing population and there is also a demographic transition in big countries including China and India. People don't live as long in these countries as in Europe or the US but their populations are five to six times larger and therefore despite lower prevalence they significantly contribute to the absolute number of cases globally. So it's not only a problem that concerns ageing European populations but a global area of concern.

If we look at European populations, we estimate that 16 per cent of the population is over 65 years old and this figure could reach 25 per cent within the next 15 years. The prevalence of Alzheimer's disease (AD) increases sharply after approximately 75, so we could count over 7 million people with AD or related diseases in the near future.

A rough estimation of the cost of primary neurodegenerative diseases is € 130 billion per year. It's very high because there is not only the issue of how to cure, but a whole context of caring for these people. With AD, it is very difficult to determine when the disease began because the onset is very insidious. There is an ever increasing level of disability, and it doesn't improve at any point. The average duration of the disease is between 2 and 10 years, during which time patients will require very special care. So, these neurodegenerative diseases have a major impact on both society and the economy.

### How is a collaborative approach beneficial when facing the challenges associated with neurodegenerative research?

To solve a question by research there are two major conditions. The first is that you need brains – that is top level researchers working together. The second is that you need a lot of investment. When both these conditions are in place, the time to discovery, and from innovation to market, is generally reduced. This was particularly clear with cancer in which the highest concentration of researchers is working. It was also seen for AIDS where there was a big mobilisation of lobby groups who influenced government to put money on the table. We are lacking both of these conditions for neurodegenerative disease. One of the major ideas behind joint programming is, because we don't have so many brains, to try to make them work together, and trying convince governments that this is a major issue that will really affect their economy over the next 40 years. The idea is to move the national budgets towards transnational projects and away from national funding for national teams, which causes fragmentation and duplications. This is really the new collaborative approach to research.

We are seeing increasing numbers of applications when we make calls and because our budget is not extensive the rate of acceptance is now less than 20 per cent. This has meant tough selection and a really high level of quality. The number of participating countries has also been increasing; at the beginning we were 11 and this has risen to 28 members. The level of commitment of each country varies but everybody wants to be in the picture, and we are beginning to see a new momentum around collaboration, though this takes time because for years these countries have worked separately. Interestingly, the weakened economic situation in Europe has not been much of a limitation. When countries put their

money into a transnational programme the pressure they feel on their own country is reduced as the responsibility is shared collectively. The international level also provides some guarantee of quality because there is less conflict of interest and less lobbying for funding. So, for some countries it's a very interesting way to use a budget that has been significantly limited by the crisis as efficiently as possible for research.

### Why did you decide to expand the JPND Scientific Advisory Board to include representatives from industry and patient organisations?

When we set up the strategic agenda, the first Scientific Advisory Board was made up only of top-ranking researchers working in the public domain on basic research. We recognised the value of working with representatives from industry, patient and carer groups, and the idea was born to have them on our Scientific Advisory Board permanently. It currently consists of two members from industry and two from the patient/carer associations.

### Do you have any examples of your supported transnational projects and specific successes achieved through these?

We have 15 international research projects currently ongoing, representing € 40 million and encompassing around 130 research partners. I will take the example of BIOMARKAPD, which was among our first projects to start and is the largest international collaborative project ever undertaken in this area. BIOMARKAPD is coordinated by Bengt Winblad at the Karolinska Institute in Sweden and aims to standardise the measurement of Alzheimer's and Parkinson's biomarkers across Europe. Scientists and physicians have been using biomarkers with the same names but are being measured differently in reality. It



is really important to synchronise these processes. The finalised results are expected in 2015, and it is predicted that they will transform the field of neurodegenerative research; improving our ability to measure disease progression and the assessment of new treatments. Twenty-one countries, including Canada, have already signed off to implement the protocols that will follow from BIOMARKAPD. This is a good example of what we can do when scientists and physicians collaborate at the transnational level.

**You conducted a mapping exercise in 2011 to provide a picture of the scale and scope of research activity in neurodegenerative disease among JPND member countries. Can you outline the results?**

The first exercise was the basis of our research strategy; we needed to find out how much was already invested and understand where the priorities lay. We began gathering this information in 2011 and estimated that across the different JPND member countries (21 at the time), and including the EC, about € 370 million per year was dedicated to research in this area. Most of it involved basic research and only a small proportion was attributed to health and social care research. It allowed us to see the kind of ongoing issues for large cohorts and big infrastructures, and to compare with other countries like the USA where the National Institutes of Health (NIH) invests around US \$400 million per year. It also showed the potential of cofunding, because all this funding – except the EC – was coming from national funds. The idea was that if we were able to divert some of this money for common projects, we would make a significant improvement. We are intending to do a new mapping exercise within the next two years.

One of the outcomes of the G8 Dementia Summit in London was that the Organisation for Economic Co-operation and Development (OECD) is preparing to launch a project in 2014, focused on AD and dementia, to strengthen international collaboration and promote data sharing. To do this they will need a G8 mapping exercise and we are helping them on this project by sharing the methodology we have developed. It will be beneficial in terms of elucidating the relevant research activities in these countries and using the same methodologies will ensure the results are comparable with ours.

**What current research are you personally most excited about?**

There are many exciting things going on, but I will highlight research in three areas of particular interest to me:

Genetics, induced pluripotent stem cells and large-scale prevention trials – I am a scientist and physician and my own research is in understanding the genetic makeup and identifying new pathways. We are benefiting from an incredible revolution through whole genome sequencing, which is creating possibilities for a whole host of ground-breaking research.

New experimental models – it's very difficult to set up experimental models to mimic complex disease and some cellular models based on induced pluripotent stem cells are very promising.

Prevention - A lot of potential risk factors have been described for neurodegenerative diseases, especially for AD. At the moment these conclusions have mostly come from observational settings so we need to set up trial prevention programmes to see whether targeting these factors reduces the prevalence of the disease. Even if you don't cure the disease but just postpone the onset by five years you can reduce the prevalence by half. This is because the disease appears at a very late age and has competitive mortality. We need large sample sizes and short follow up times as the impact will be large at the population level but will have a small effect on individuals. The only way to have large enough cohorts is to do this at the European level. This will give us sufficient evidence to make decisions on prevention strategies more rapidly.

## FOCUS ON PRIORITIES

JPND's Strategic Research Agenda sets out the programmes' core priorities and the key activities to support them

**WHEN THE JPND** was established, the Scientific Advisory Board helped identify five big thematic priority areas for future research through consultation, brainstorming and discussions with stakeholders:

- The origins of neurodegenerative disease
- Disease mechanisms and models
- Disease definitions for diagnosis
- Therapies and prevention strategies
- Healthcare and social care

The Scientific Advisory Board then came up with nine crosscutting activities to enable forward motion with the thematic priorities:

- To know our research capability so we can invest in the right places
- To support infrastructures and platforms
- To partner with industry – who have the brains, money and know how to develop treatments and drugs
- To work with regulatory organisations – to protect patients for example specific ethical boards for clinical trials
- To develop partnerships outside Europe
- Capacity building
- Education and training
- To connect with policymakers and convince them to invest in our strategy
- To communicate and disseminate information about the advances of research



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