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DEMENTIA IN EUROPE

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talks about the Innovative
Medicines Initiative



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discusses the progress
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Tackling neurodegenerative diseases

Professor Adriana Maggi, University of Milan & Vice-Chair of the EU Joint Programme – Neurodegenerative Disease Research (JPND) Management Board, talks with Alzheimer Europe about the progress made to date, projects being supported by the JPND and the role of patient and carer organisations can play.



Alzheimer Europe: JPND is the largest global research initiative addressing the challenge of neurodegenerative diseases, particularly Alzheimer's disease. What progress has been made in the last year?

Adriana Maggi (AM): JPND is a global initiative led by EU Member States, which is bringing countries together to align their common strategic goals in order to tackle neurodegenerative diseases – a problem which no country can address alone. JPND wants to tackle the growing burden of these diseases, so we have to support the full spectrum of research that is required (i.e. basic, clinical and healthcare/social research). JPND is also encouraging the development of national plans for neurodegenerative diseases, and is aligning national resources and initiatives in this area, with a focus on linkage, harmonisation and data sharing.

The past 12 months have seen JPND countries work together very effectively in a number of priority areas. Long-term, medium-to-large-scale programmatic initiatives are moving forward in parallel, creating the necessary trust and alignment between the 27 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 are currently open in the areas of “Preventive strategies” and “Cross-disease analysis of pathways”.

- Alignment Actions to determine research needs and opportunities in areas such as Longitudinal Cohort studies, Animal and Cell Models and Assisted Living Technologies.
- Action Groups to promote engagement and partnership, including with the European Commission and other international organisations.

These JPND actions, among 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 EUR 100 million in total due to be made available. Importantly, this funding will be in addition to, not instead of, other neurodegenerative disease funding.

AE: Can you give us some specific examples of these Alignment Actions?

AM: All of the Alignment Actions are being chaired by JPND Management Board members, and are highlighted in the table below. Two of the most advanced actions are in the areas of Animal and Cell Models and Longitudinal Cohort Studies:

Longitudinal Cohort Studies

The JPND Action Group on Longitudinal Cohort studies has investigated potential actions for both disease-based and population-based longitudinal

cohort studies, looking at whether current member-led or EC-supported activities can be expanded or better exploited, or new activities identified. Action Group discussions during 2013 were focused on:

- Taking stock of current longitudinal cohort studies for both neurodegenerative disease-based and general population studies of relevance
- Determining how JPND adds value to existing cohort investments
- Identifying gaps and cases for new activity in areas of unmet need
- Scoping the emerging scientific opportunities

A copy of the report which was endorsed by JPND Management Board in October 2013 is available on the JPND website. The report brings together in one place for the first time the wealth of cohort opportunities for neurodegeneration research across JPND countries. It spans general population-based,

targeted (preclinical) and disease-focused cohorts. Immediately available are the analyses presented in the report and listings of imaging studies and existing cohorts across Europe, with web references. Implementation plans will be announced later in 2014 once priorities for action have been decided. Recommendations span coordination, funding and policy areas.

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 physiopathological information, they do not point to a clear therapeutic pathway.

JPND Alignment Actions	JPND Chairperson
Investigating where current member state-led or EC-supported longitudinal cohort studies can be expanded or better exploited, or new activities identified	Rob Buckle <i>United Kingdom</i>
Defining concrete approaches for alignment of national research initiatives and activities, focusing on areas with high potential for international cooperation and feasibility for alignment. The first area targeted has been neuroimaging.	Etienne Hirsch <i>France</i>
Identifying new lines of intervention for Animal and Cell Models	Adriana Maggi <i>Italy</i>
Working in a collaborative fashion with the Ambient Assisted Living Joint Programme (AAL JP) to meet user needs for neurodegenerative diseases	Jaqueline Hoogendam <i>The Netherlands</i>
Increasing coordination of research into palliative care	Enda Connolly <i>Ireland</i>
Promoting the involvement of patients and the public in neurodegenerative disease research	Mogens Horder <i>Denmark</i>
Encouraging partnership with the European Commission and other relevant international initiatives	Philippe Amouyel <i>France</i>

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. The call should also support the organization of interactive online workshops on experimental models for the study of neurodegeneration.

National Strategies

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 countries' participation in JPND, and will focus resources on tackling neurodegenerative diseases nationally, aligning with the European Research Strategy. Several new, related strategies (e.g. the Dutch Deltaplan for Dementia, 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.

International Partnerships and Sustainability

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 recent G8

Dementia Summit in London as an example of successful international cooperation in dementia research, and we look forward to working with the new global plans and initiatives emerging from the summit. JPND is actively discussing partnership with the European Commission and has organized a number of engagements with senior representatives to date. 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.

AE: When we last spoke with you, the first call for projects had gone out which focused on the use of biomarkers in the area of neurodegenerative disorders. What has been the result of that call?

AM: EUR 16 million in total was made available for that call (from all participating countries) and four projects began their work in 2012. These three-year projects are aiming to optimise biomarkers and harmonise their use in a number of neurodegenerative diseases including Alzheimer's, Parkinson's, motor neuron diseases, sporadic Creutzfeldt-Jakob disease (sCJD), and rapid progressive dementias in the young. Bengt Winblad of the Karolinska Institutet, Sweden is interviewed later in this article



Prof. Adriana Maggi, presenting JPND at the “Healthy Brain, Healthy Europe Conference, organised by the Irish EU Presidency and the European Commission, during the European Month of the Brain, June 2013 in brain reser

about the largest of these projects – BIOMARKAPD, which is focusing on both Alzheimer’s disease and Parkinson’s disease.

AE: What other projects are currently being supported by JPND?

AM: 11 new international research projects will begin in 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 health care policies, strategies and interventions”. The successful 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. 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, EUR 3 m 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.

AE: What is the role that patient and carer organisations such as Alzheimer Europe play in the overall strategic research agenda and the specific projects?

AM: Patient and carer priorities are very important to JPND. A specific JPND consultation process identified patient/carer priorities in 2011 and these were translated into specific priorities within the JPND Research Strategy. Since the launch of the strategy in early 2012, JPND has expanded on that direct engagement by modifying the membership of its Scientific Advisory Board (SAB) to include scientific representatives from patient-led organisations and industry. Indeed, Alzheimer Europe’s current Honorary Secretary, Prof. Charles Scerri is now on our SAB! Having scientific representatives from patient organisations on our SAB will ensure that JPND continues to prioritize research areas such as improving the social care structures available to assist patients, their families, and health service providers so that patients can receive optimum care at all stages of their illness. The recently appointed new SAB members are:

- Charles Scerri (Alzheimer Europe)
- Brian Fiske (Michael J Fox Foundation for Parkinson’s Research)
- Eric Karran (Alzheimer Research UK)
- François Nicolas (GE Healthcare)
- Thomas Rooney (Sanofi)

JPND MB members have also determined that

patient and public involvement (PPI) in research should be an integrated part of SRA implementation, and a specific JPND Action Group has been working since 2012. The group is charged with “promoting public involvement in research in order to improve the way that neurodegenerative disease research is prioritized, commissioned, undertaken, communicated and used”. The Action Group is currently engaging with relevant external stakeholders, disseminating a plan for PPI, in order to obtain advice on implementation at the national and institutional levels. In addition, patient and carer organisations such as Alzheimer Europe will also continue to play a vital role in our engagement process to facilitate cooperation, two-way communication, knowledge transfer, as well as consultation on JPND plans and initiatives.

AE: JPND launched two Joint Transnational Calls in late 2013. What are the priorities for these calls and the expected results?

AM: The 2013 JPND Annual Calls for proposals are calling for European research projects in the areas of “Cross-Disease Analysis of Pathways related to Neurodegenerative Diseases” and “Pilot Studies on Preventive Strategies related to Neurodegenerative Diseases”. Both Calls were launched in December with a first-phase (pre-proposal submission) deadline of mid-February 2014. For both calls, JPND is piloting the use of a new online partnering tool. It is believed that this tool will especially benefit early-career researchers and research groups not normally included in established consortia.



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Interview with Bengt Winblad, Coordinator of the JPND-supported BIOMARKAPD project

Transforming research on Alzheimer's and Parkinson's Disease



Prof. Bengt Winblad,
Karolinska Institutet, Sweden

After a decade of disappointing drug trials, European researchers are finding new ways to understand Alzheimer's and Parkinson's disease, just in time for the anticipated "tidal wave" of cases.

With worldwide cases expected to triple by 2050, it is widely accepted that early diagnosis of Alzheimer's and Parkinson's disease will be vital to tackling these neurodegenerative diseases. The goal of new clinical trials in this area will be to treat early-stage patients with drugs that inhibit the destructive process before too many neurons have been lost. However, as the clinical symptoms in these early stages may be very subtle, or even absent, the tools currently used to diagnose these diseases cannot be relied upon for these new trials.

According to Bengt Winblad of the Karolinska Institutet in Sweden "research tells us that instead of the current tools, we could use biomarkers to determine if someone has Alzheimer's or Parkinson's". Ranked by the Journal of Alzheimer's Disease as the world's most prolific Alzheimer's researcher, Winblad is coordinating one of the largest international collaborative projects ever undertaken in this area. The goal of the three-year "BIOMARKAPD" project is to standardize Alzheimer's and Parkinson's biomarker measurements across Europe. Supported by 19 different countries under the JPND initiative, the project results are predicted to transform the entire field of neurodegenerative disease research – leading to more definitive diagnosis, greater ability to measure disease progression and better assessment of new treatments.

"Nuts-and-bolts" science

Established biomarkers exist for early Alzheimer's and promising candidates are underway for early Parkinson's. However, a major problem today is the large variation that exists in biomarker measurements between different studies, centres and laboratories, which seriously jeopardizes their introduction into both clinical routines and clinical trials around the world. Standardizing biomarker measurements across Europe is a tricky business, and first requires standardized protocols on how to collect clinical samples from patients, how to perform the measurements and how to interpret the results. It is the veritable 'nuts-and-bolts' science – unglamorous but essential. However, such is the anticipated impact of the project

results that world-leading laboratories from 21 countries (including Canada) are signed up to implement the BIOMARKAPD protocols.

Speaking at the project's most recent general assembly in Barcelona, Winblad firmly believes that the resulting standards will have a major influence on clinical research and drug development for neurodegenerative conditions in general and for Alzheimer's and Parkinson's in particular. "The active involvement of all European JPND countries in the project not only provides enormous expertise, but also ensures that protocols developed can be applied by all the member states," he says.

New Biomarkers

Whereas BIOMARKAPD is focusing on existing biomarkers in the spinal fluid of patients with Alzheimer's or Parkinson's disease, the project will also support the development of new promising biomarkers through its newly-created biobank, located in Luxembourg. The biobank will contain samples from Alzheimer's and Parkinson's patients, including patients in very early disease stages, as well as healthy controls. The project will look to make these samples available to the scientific community to conduct field-changing research such as developing new assays and testing new biomarker candidates.

Why has this not happened until now?

The development and standardization of biomarkers typically demands significant financial and intellectual resources, and for individual research groups it does not offer the short-term rewards and long-term competitive advantage often used to assess decisions to commit resources. "In light of the urgent need for optimized and standardized Alzheimer's and Parkinson's biomarkers and the ambitious goal of BIOMARKAPD to meet that need, it is fitting that multiple partners mobilize under the JPND umbrella, and through a coordinated effort, share the expense, risk and, ultimately, the benefits of the research," says Winblad. "The JPND is well-positioned to lead the push and marshal the necessary resources to make projects like this a reality," he said.

With Winblad at the helm, BIOMARKAPD seems to be well on its way to achieving its goals.