JPND: The largest global collaborative initiative for neurodegenerative disease research

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Chairman for the global initiative EU Joint Programme – Neurodegenerative Disease Research (JPND) Professor Philippe Amouyel brings to light their innovative work in neurodegenerative disease research

JPND is the first and largest global collaborative research initiative established to tackle the growing challenge posed by the increasing prevalence of neurodegenerative diseases (ND) worldwide.

ND are debilitating and largely untreatable conditions that are linked to age and the regular increase of life expectancy globally. Amongst these, dementias account for the greatest burden: 50 million people worldwide are living with Alzheimer's disease and related disorders. By 2050 in Europe alone, the number of cases will triple and the global total direct and informal care costs for Alzheimer's and Parkinson's disease are estimated to surpass €2,000 billion per year. Solutions are likely beyond the scope and resources of any single country. This common challenge can only be confronted by the maximising of a collective potential at both a European and global level. This joint programming initiative leverages on three pillars: a shared vision, a light and robust management and a common Research and Innovation Strategy (RIS) agenda.

Increase coordination and investment

Initiated in 2009 under the auspices of the European Commission, JPND aims to increase coordinated and defragmented investment between participating countries in research aimed at finding causes, developing cures and identifying appropriate ways to care for those with ND. Its goal is to accelerate the discovery of cures and to enable early diagnosis for early personalised treatments. It also seeks to implement solutions that can alleviate the plight of families and the economic burden brought about by ND.

“The challenge is to tackle neurodegeneration, and in particular, Alzheimer’s disease through an unprecedented collaboration at the European level and beyond. The ultimate goal is to facilitate the cooperation of researchers, to reduce fragmentation, to prevent unnecessary doubling of efforts and to pool and organise resources on a voluntary basis for the benefit of the populations.” – Professor Philippe Amouyel, JPND Chair, University of Lille (France).

In 2019, JPND renewed its Research and Innovation Strategy (RIS) agenda, building on the framework that was established in the original Research Strategy of 2012. The renewed RIS updates the common vision of the 30 JPND member countries, providing a strategic approach to support world-class research and innovation to promote and accelerate the exploitation of scientific opportunities, confront barriers to progress and define novel approaches to prevention, intervention, treatment and care.

Shaped by major advances, the RIS showcases research areas that have been transformed by data science since the 2012 edition.(1) It also identifies **five thematic priorities for future research.**

“One of the major visible successes of JPND was that it brought together literally hundreds of scientists in Europe who very likely would not have collaborated without the JPND calls, or at least to a much lesser degree. JPND transnational calls have been extremely popular. The calls sparked collaborations and innovative research approaches even for consortia that did not get directly funded, simply by bringing researchers together.” –

Professor Thomas Gasser, JPND Scientific Advisory Board Chair, University of Tübingen, Germany.

JPND and the future of brain health

Originally a European member-state led initiative, JPND is today a global initiative with 30 participating countries.(2) In its continuing efforts of global outreach and in addition to more actively engaging non-EU countries around Europe, JPND also extends its outreach initiatives to Asia.

Increasing life expectancy without disability is closely dependent upon our **brain health** and one of the key challenges embraced by JPND in its fight against ND. Brain disorders, encompassing neurological and mental health disorders, represent the largest cause of DALYs in 2015 (10.2% of global DALYs) and the second-largest cause of global deaths (16.8% of global deaths). For the last ten years, both European Commission- (EC) and Member States- (MS) led initiatives have been established in Europe, to collectively face these challenges: JPND on ND research; NEURON, an EC ERANET partnership supporting basic, clinical and translational research in the fields of brain health other than ND; the Human Brain Project, an EC’s Future and Emerging Technologies Flagship funded by the seventh framework programme that aims to put in place a unique Information and Communications Technology-based infrastructure for brain research. In 2019, all three initiatives, together with the **European Brain Council**, started discussions in the context of a European Brain Research Area EC Coordination and Support Action, to find operational synergies, identify a gap and foster alignment across European and global brain initiatives.

The time has come to improve alignment and synergies across these initiatives, to minimise time-to-market of preventions and treatments by intensifying scientific collaborations, identifying gaps in knowledge, improving data sharing and facilitating access to infrastructures on the model of JPND. The extent of the challenge and the complexity of the brain health issue requires a highly visible support system and a defined and organised scientific and innovation strategy. A sustainable holistic view of the RIS like the one supported by JPND, is also necessary in brain health.

There is a pressing need to capitalise on the experience and trust that have been built among European and non-European countries through these existing initiatives. The time has come to form a more ambitious one by mobilising all stakeholder resources under a common transnational banner that will catalyse this unique momentum and accelerate the creation of the largest competitive European and global collaboration essential to improving brain health. Only by maximising our collective potential can this global challenge be confronted.

References

1 Research areas transformed by data science: i) Use of artificial intelligence (AI) technologies for medical care and research; ii) explosion of capability in digital health; iii) growth in public-private partnerships.

2 These include twenty-three EU Member States (Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, Netherlands, Poland, Portugal, Romania, Slovak Republic, Slovenia, Spain, Sweden, United Kingdom) four Associated Countries (Albania, Israel, Norway and Turkey) and three Partner Countries (Australia, Canada and Switzerland). In 2018, a collaboration with the National Institute of Ageing (NIH) in the US was realised which will be renewed in 2020.

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Editor's *Recommended* Articles

Creating a major impact on neurodegenerative research funding in Europe

December 15, 2020

JPND promotes the strategic alignment of neurodegenerative disease research by bringing together funders and researchers to create a major impact on the fight against neurodegenerative diseases in Europe.

JPND, the largest global collaborative initiative for neurodegenerative disease research, creates a major impact on neurodegenerative research funding in Europe

JPND's unique programme enables the 30 participating countries1 to collaborate on tackling the challenge of age-related neurodegenerative disease (ND).

JPND is a non-binding collaboration relying on trust among its members who engage voluntarily on a shared vision, a reactive management structure and a common Strategic Research and Innovation agenda (SRIA).

Four bodies for a smooth and efficient management

The management structure of the JPND initiative comprises four bodies: a Management Board, an Executive Board, a Scientific Advisory Board (SAB) and a Secretariat. The Management Board is the decision-making body. It seeks advice from the SAB on the SRIA and related matters. The Management board elects a Chair and a Vice Chair to coordinate the activities of JPND. The Executive Board supports the Management Board in all aspects concerning the preparation and implementation of decisions. The Secretariat organises the day-to-day management of the different structures and implements tasks assigned to it by the Management Board and the Executive Board.

The JPND Management bodies exert their mandate with the utmost regard to transparency and fairness. Decisions are governed by equal treatment (one country, one vote) and take into account all ethically relevant aspects.

Transnational actions to promote strategic alignment of research across Europe

Based on the SRIA, JPND members have developed an implementation plan that is regularly updated, prioritising the topics that will be addressed. Every year, JPND member countries agree on one or several topics. The implementation of these topics is supported by alignment action initiatives, international working group calls and joint transnational calls.

JPND is promoting the strategic alignment of research across Europe though a number of actions for example, longitudinal cohorts, imaging infrastructures and public patient involvement.

JPND supports the organisation of international working groups through calls for proposals intended for the scientific community. The results of these international working groups enable the identification of the needs and the gaps that will consequently allow JPND to better target its future actions that are mainly supported by its annual joint transnational calls.

JPND funding: a “virtual common pot”

Since the very beginning, JPND has regularly received the support of the European Commission (EC). To achieve greater consistency with the strategies and actions of JPND and to maintain a certain level of sustainability, the JPND management has been supported through dedicated coordination and support actions funding by the 7th and 8th EC work programme (Jumpahead and JPsustaiND).

Concerning the international working group and joint transnational calls, JPND supports highly competitive transnational collaborative projects that link research teams from several countries by juxtaposing large national research grants. In doing so, JPND has created a virtual common pot that efficiently supports each team of researchers towards a shared objective. Each JPND country engages voluntarily and on a variable-geometry basis according to her own national priorities. Interested countries participating in these calls earmark a dedicated budget.

Research projects are selected by an international and independent common review board comprising recognised scientific experts from all participating countries. From this, a ranking list, based on scientific excellence, is provided. Selected national teams will then receive the budget from their respective countries. This unique alignment strategy allows for a major leverage effect on the total amount of funds each research programme can receive, largely of €1 million. The funds that a JPND member country earmarks for joint transnational calls can be allocated only to research teams based within that country.

As JPND projects are by definition multi-national, some projects, albeit being ranked high in excellence, cannot be funded because the country of one or more of the project’s partners did not earmark enough budget to fund its local teams. This is where the EC’s top-up fund scheme enabled by its co-funded partnerships (ERANET Cofunded calls: JPco-fuND and JPco-fuND 2) allows to bypass this limitation and to significantly increase the number of supported teams. This EC common top-up funding can be allocated to any country to fill the remaining gaps in the ranking list and increase the number of highly-ranked supported projects.

“There are very high numbers of people with devastating brain diseases such as various forms of dementia and other neurodegenerative disorders. Patients and their families often suffer for years, and public funding for research into these diseases is indispensable for fighting them. JPND is our best chance to jointly and globally act and to follow our common aim,” says, PD Dr Marlies Dorlöchter, DLR Programme Management Agency, Germany and JPND Executive Board member.

A major impact on neurodegenerative research funding in Europe

As of today, JPND has funded some 121 research projects, gathering more than 600 research teams, representing around €175 million of funding. More than 4,800 individual research teams have applied to the different JPND joint transnational calls. JPND has mapped the current landscape in neurodegenerative disease research amongst member states in 2011 and 2016 in terms of funding. In 2016, the total research portfolio was calculated at €2,217 million (€566 million/year): a 53% increase on overall annual investment reported in 2011 (€370 million/year). Annual spending on investments >€500k increased by 55% (€150 million/year), with a similar increase (48%, €46 million/year) observed for investments <€500k since 2011.

Notably since 2011, an approximate two-fold increase in annual spending on clinical and health & social care research as a proportion of total funding was reported, with a small decrease in basic research spend. Greater involvement of JPND member countries in larger research projects was observed, with 81% of countries contributing to at least one investment >€500k, representing a 15% increase from 2011.

Clearly, JPND calls were a major factor in this change, achieving its primary goal to increase coordination and reduce fragmentation in Europe and beyond.

References

1. These include twenty-three EU Member States (Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, Netherlands, Poland, Portugal, Romania, Slovak Republic, Slovenia, Spain, Sweden, United Kingdom) four Associated Countries (Albania, Israel, Norway and Turkey) and three Partner Countries (Australia, Canada and Switzerland). In 2018, a collaboration with the National Institute of Ageing (NIH) in the US was realised, which will be renewed in 2020.

JPCOFUND –

Grant agreement ID: 643417

JPSUSTAIND –

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JPND: Enabling collaborative research in Alzheimer's and Parkinson's diseases

June 25, 2021

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Professor of Neurology Thomas Gasser, JPND's Scientific Advisory Board Chair and Director of the Department of Neurodegenerative Diseases, shares in an interview JPND's innovative research and collaboration efforts in the universal race against Alzheimer's and Parkinson's diseases

JPND is more committed than ever to its pertinent work facilitating unprecedented collaboration amongst researchers at a European level and beyond. Around 50 million people worldwide are living with Alzheimer's disease and related disorders today. By 2050 in Europe alone, the number of cases will triple and the total of global direct and informal care costs for Alzheimer's and Parkinson's diseases (AD and PD) is estimated to surpass €350 billion per year. (1)

What are the most pressing needs in both Alzheimer's and Parkinson's diseases research today, and JPND's role in addressing this?

Professor Gasser: "The most pressing needs for AD and PD seem to be:

- An early, at best pre-symptomatic diagnosis.
- Relevant markers to reliably monitor relevant aspects of disease progression.
- The establishment of effective disease course modifying, or even preventive, treatments.

It is often assumed that the first two are prerequisites of the third, which is of most urgency to both the patients and their families.

In addition to these ambitious goals, many more needs must also be addressed, which may be of more immediate benefit to the patients and their families such as:

Professor Thomas Gasser

- Recognising the present limitations of healthcare systems to ensure access to the most effective symptomatic treatments across all member states of JPND.
- Exploiting the potential of non-medical approaches, e.g., a better management of social and psychological burden of these disorders on the patients and their relatives."

What impact has JPND made on the progress of neurodegenerative disease research, in particular AD and PD, in the last five years?

Professor Gasser: "JPND has created the feeling of a joint mission in research communities to address relevant questions in neurodegenerative disease research across Europe in a spirit of cooperation. This can be documented by a measurable increase in funded research projects in the field of neurodegenerative diseases across many member states.

In terms of scientific output, some of the most relevant advances have been made for example, in the field of standardised assessments of progression biomarkers, in neuroimaging, or in the understanding of the role of inflammation or other basic biological mechanisms across different neurodegenerative diseases. Within one early project (BIOMARKADP), a "virtual biobank" has been created, joining clinical information on over 8600 subjects with varying diagnoses from 21 local biobanks. Sample requests can be placed via a publicly available website. (2)

The JPND biomarker projects have helped to diminish the barriers associated with the use of CSF biomarker analysis by generating consensus recommendations on their clinical interpretation and application for dementia diagnosis. In a survey of clinical dementia experts, 74% of respondents (total n = 51) use CSF biomarkers in clinical practice and 69% perform lumbar punctures on an outpatient basis. Most use CSF biomarkers to diagnose atypical (84%) and early-onset cases of cognitive impairment (71%) and for the differential diagnosis of other dementias (69%)." (3)

JPND is aligning its initiatives towards Brain Health with other EU initiatives. Can you share your thoughts about this and its benefits towards AD and PD research?

Professor Gasser: "Alongside other EU initiatives such as Neuron, Human Brain Project, and European Brain Council, JPND is a partner of the European Brain Research Area EU (H2020 GA no. 825348). This project was created as a catalysing initiative for brain research stakeholders (including researchers, clinicians, patients, governments, funders and public institutions) to improve the coordination of brain health research across Europe while fostering global initiatives.

Among its different tasks, EBRA aims to identify research opportunities and research and innovation gaps to be addressed in the field and to provide recommendations on future areas for excellent, innovative, and translational brain research in Europe. This means that research into the brain, its function and its diseases is no longer divided into different initiatives. Therefore, this can increase the impact of all research programmes if it is effectively communicated. The need remains high, and AD and PD research could benefit from a more integrated approach."

What are the major challenges that lie ahead for Alzheimer's disease and Parkinson's disease research and how can JPND continue to make an impact on these?

Professor Gasser: "JPND's commitment to making an impact for ND diseases can be seen in its decision to explore synergies with existing platforms. Some examples are the 2018 European Strategy Forum on Research Infrastructures Roadmap and the Human Brain Project, where the integration and harmonisation of data and materials are encouraged. Furthermore, promoting an open-access approach to sharing and pooling of data and resources is also a focal point. With the advent of artificial intelligence (AI), as a tool across all domains of research, AI will need careful adaptation for ND research, taking into account the ethical, legal and societal implications of the technology.

Through its 2019 Research and Innovation Strategy, JPND aims to create an environment to enable and facilitate research in key areas. Some of these include ensuring supportive infrastructure, providing partnerships with industry and fostering innovation, working with regulatory organisations and enabling international partnerships. (4)

The ageing of the European societies demands urgent research into novel effective treatments. The enormous progress that has been made in many areas of basic neuroscience but also in other fields such as data science, AI, in imaging and the development of highly efficient and specifically targeted modification of gene expression, as exemplified by RNA-treatments, will challenge the neurodegenerative diseases research communities to embrace these opportunities and integrate them into their approaches."

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Editor's *Recommended* Articles

Patient and Public Involvement at the heart of brain research

September 7, 2021

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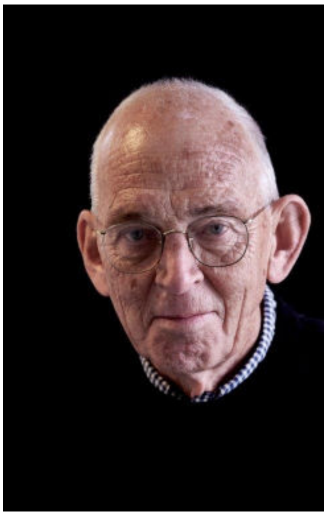
Professor Mogens Hørder, PPI expert, JPND's management board member and representative of member state Denmark, discusses how Patient and Public Involvement (PPI) is at the heart of neurodegenerative disease research

In the last 20 years, Patient and Public Involvement (PPI) has become an indispensable component of health and healthcare research. PPI aims to turn the focus of research towards the patient. The EU Joint Programme Neurodegenerative Disease Research (JPND) developed a PPI strategy in 2015 for the implementation of PPI as part of JPND's annual calls and as a learning process. PPI expert Professor Mogens Hørder, JPND's management board member and representative of member state Denmark, talks about JPND's strategic approach to incorporating PPI into Neurodegenerative Disease Research.

What is Patient and Public Involvement in Research (PPI) and why is PPI part of the JPND strategy?

With PPI, the patient becomes a partner in the planning and conduct of research. The patient has experiential knowledge from living with the disease, which complements the academic knowledge of the researcher. This partnership potentially widens the goal of the research to include the precise needs of patients. The patient may contribute to the various stages of the research project, from its design to its dissemination and finally, the implementation of the project outcomes.

How has PPI been developed by JPND?



Professor Mogens Hørder

JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. Originally a European member-state led initiative, JPND is today a global initiative with 30 participating countries. The introduction of PPI in research funded through JPND calls understandably results in a wide variability in researchers' definition and knowledge of PPI, and an even greater variance in their experience of applying PPI to research. PPI originated in the Anglo Saxon part of the research community in the 1990s.

Since then, its dissemination has taken place. However, when JPND initiated its PPI strategy in 2012, PPI remained very much a distant concept only, to most researchers. Much emphasis has been placed on the engagement of the representatives of the JPND Member States. The implementation of PPI should be seen as a learning process, firstly among the members of the Management Board and subsequently among researchers from the 30 countries.

In 2012, PPI was brought up for consideration by the JPND Management Board and discussed again with JPND's Scientific Advisory Board. As a result of these discussions, an Action group for PPI was established, leading to recommendations for a strategic approach to PPI. Support for the further development of PPI came from the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN) funded by the Department of Health in England.

DeNDRoN supports the development and delivery of clinical research in the fields of dementia, Parkinson's disease, Motor Neuron disease, Huntington's disease and other neurodegenerative diseases in the English health service, NHS. A JPND Advisory Group on PPI gave feedback on the recommendations for the implementation of PPI in JPND research by the Action group.

JPND's Strategy for PPI and its implementation

By 2014, a strategy for the implementation of PPI in JPND Calls for Research Proposals was confirmed by the JPND Management Board. The implementation of PPI as part of JPND Calls was applied for the first time in the 2015 Call.

PPI is integrated into the Call Process through four steps:

Step one involves the application for funding by the pre-selected consortia. In the full application, researchers must describe how they have planned for PPI in the proposed project, if and how PPI is considered during the development of the idea for research and the conducting of the project.

Step two is a systematic review by a PPI secretariat of how PPI was planned by the consortia. The outcome of the review is a ranking of each application in one of the following three categories: A) satisfactory plan for PPI, B) plan for PPI may be improved, C) unsatisfactory or missing plan for PPI. The outcome of this ranking is considered by the scientific review panel as part of the overall rating of the application.

Step three involves the actual application of PPI by the researchers. Each research consortia with a proposal funded through JPND comprises partners from at least three different countries. The knowledge and experience of PPI differ greatly across the JPND member countries. Collaboration on PPI among the partners of the consortia supports the dissemination of knowledge and learning about PPI.

Step four involves the follow-up by the JPND PPI Secretariat on what took place during step three. This is done after year 1 and year 4 of the research project. From these follow-ups, information about the way PPI has been applied is identified and can serve as shared information on the progress of PPI application over time. The most relevant part of this information will be available on the JPND website as support for future applicants.

What has been achieved and what comes next?

A systematic review of PPI of the proposed projects for funding has shown that between 60 – 80 % of the proposals have a satisfactory plan for PPI. Less than 5% of these proposals have missing or unsatisfactory PPI.

After year one of funding, most projects still adhere to their plans for PPI. With respect to PPI conduct, often, only one representative country instead of every country of the consortium is responsible. As of now, more follow-ups need to be done to accurately assess the impact of PPI on projects (usually over a period of at least 5 years).

Over the next 4 to 5 years, knowledge and experience from the 2016 to 2020 JPND Calls will be made available on JPND's website, providing a source for shared learning for all researchers taking part in projects funded through JPND.

Benefits of PPI

PPI in research is mutually beneficial to both patients and researchers. PPI provides researchers with insights into how it is to live with a particular condition, which in turn helps ensure the relevancy of research design, conduct and implementation and improve the quality of healthcare research. Simultaneously, involving patients in research brings health benefits to both patients and their families as they feel empowered in having voice-over decisions and actions concerning their own health.

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More About Stakeholder

JPND research

The EU Joint Programme – Neurodegenerative Disease Research (JPND)

JPND – finding cures for neurodegenerative diseases and working to enable early diagnosis for early targeted treatments with worldwide collaboration.

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JPND: Neurodegenerative disease research without boundaries

February 21, 2022

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Jacqueline Hoogendam, JPND's newly elected Vice-Chair and Executive Board member talks about JPND's past and present strategies in its outreach campaign within and beyond Europe

Initiated early 2009, JPND started out with 10 participating countries as members. Today, the world's first and largest global neurodegenerative research initiative boasts an international presence with its 30-member strong participating countries.

JPND: In what ways has JPND been successful in its outreach efforts beyond Europe?

JH: In 2009, there were 10 JPND members comprising EU member states, associated countries, and Canada, as a third country member, showed interest in participating. Indeed, a third country policy allowing non-EU member states/associated states to participate in JPND was developed. Australia followed suit as a third country member.

Discussions with US representatives soon revealed the challenges JPND was to face in its quest to becoming a truly global organisation. US-regulations on funding research projects make it virtually impossible for the USA to join JPND as a third country member. However, JPND soon found a solution to enable collaboration, thanks to the creative minds of its partners at the National Institutes of Health (NIH) and the National Institute on Aging (NIA).

Ideas on the subject of future calls for research proposals were exchanged and the idea to launch similar calls simultaneously was explored. Both NIH/NIA and JPND invited the PIs of their funded projects to look into collaboration possibilities with projects driven by similar goals and funded by JPND and NIH/NIA respectively.

JPND: In your view, how has JPND's international outreach strategy helped it to achieve some of its objectives?

JH: The ultimate goal of JPND is to find cures for neurodegenerative diseases and to enable early diagnosis for early targeted treatments. However, it is not possible to give definitive predictions on how long this might take to happen.

Our current strategy is to increase coordinated investment in neurodegenerative disease (ND) research aimed at finding causes of disease, developing cures, and identifying appropriate ways to care for those with ND. In this our immediate goals are:

- To add value to national investments through coordinated action;
- To encourage the development of national research strategies in ND;
- To engage in partnership to reach the full potential of JPND.

With the growing number of JPND members, including Canada and Australia, the investment in ND research through joint transnational calls has increased. As of now, the total investment is 190 million euros. With its annual transnational calls for research projects and its offer of research databases, **JPND is now a reference for European and global knowledge and is an innovation platform in the area of neurodegenerative diseases.** Nearly all JPND member states have a national research strategy in ND. A good example of this would be the Expert Center for Young-onset Dementia in the Netherlands, whose research agenda is explicitly based on the JPND Strategic Research and Innovation Agenda (SRIA). As a matter of fact, the national dementia research programme 2021-2030 in The Netherlands, with a total budget of over €150 million, is based on the JPND SRIA.

JPND: Can you share with us your efforts to engage Japan as part of JPND's strategy on international outreach?

JH: It is a challenge to engage countries with cultures quite different from the western European cultures familiar to me. It takes time to make connections with the right persons, to build a relationship with them and to find common grounds in research priorities. We may have found these common grounds in the World Wide Fingers studies in which Japan participates with J-Mint and where JPND funds the EURO-Fingers project.

Working towards Japanese engagement in JPND requires small steps, including gaining trust and confidence in the success of a future collaboration. Starting with collaboration on a project level and building on that towards engagement on a larger scale.

Jacqueline Hoogendam, JPND's newly elected Vice-Chair and Executive Board member

JPND: Name some of the international outreach efforts JPND continued with in spite of the challenges posed by Covid-19.

JH: Covid-19 posed huge challenges to the entire society. After recovery from the initial shock, it turned out that part of our activities could be resumed. Thankfully with the internet and the possibility of web conferences, we were able continue the bilateral contacts with a number of countries, including Japan. We hope to resume 'real' and more effective meetings soon.

JPND: What are some of the immediate and future plans JPND has to achieve greater and more effective mobilisation of research resources both within and beyond Europe?

JH: We plan to intensify bilateral contacts with various countries, focussing on their specific research capacities and connecting with their government's policies. As for new contacts, we use available networks, for instance in the World Dementia Council in which JPND has a seat. The Dutch government planned a conference aiming to increase the international investment in ND research, especially by the G20-countries. The JPND activities were to have an important role in this conference. Due to Covid-19, this conference had to be postponed, however, the intention is to hold it in the second half of 2022.

JPND: What is your strategy to convince more EU-13 countries to participate in JPND?

JH: I think a universal strategy to engage EU-13 countries won't work. Each country requires a made to measure approach. A JPND working group is currently working on these approaches, in which we will involve JPND colleagues from these countries.

One approach to be considered, is through designated events (satellite to bigger ones or standalones) with the main purpose of informing and promoting collaboration and participation in JPND. We will also link with the widening initiatives for these countries in our calls, with the purpose to make these more effective.

We will persevere in our efforts to increase the number of countries participating in JPND because we are convinced that if we work together to tackle the huge global challenge of the sustained growth of neurodegenerative diseases, we will find solutions and treatments more rapidly.

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JPND: Towards a stronger brain health partnership

June 20, 2022

One of JPND's key objectives is to fortify its work in brain health partnerships in Europe to better combat the challenges of neurodegenerative disease (ND)

Neurodegenerative disease (ND) in Europe is synonymous to the next health challenge with huge and mounting social and economic costs. As a joint-programme ND research initiative, JPND has been set up to tackle this challenge by strengthening brain health partnerships in Europe. OAG talks to JPND's Chair, Philippe Amouyel (PA), to find out how.

Philippe Amouyel

Please share with us the landscape of brain health in Europe

PA: In Europe alone, there are 380 million patients suffering from brain diseases. An average of 800 billion euros is spent in Europe annually to treat these diseases and the last COVID19 pandemic has added to that burden in terms of brain diseases. The economic and social burden in facing them will only continue to grow; therefore, it is crucial that there is alignment in ND research and partnerships towards brain health that will help address and alleviate the **increasing societal and economic burdens of brain disorders.**

How can Europe address the challenges of brain health?

PA: Europe can address the challenges of brain health by capitalising on existing international initiatives, facilitating access to infrastructure and resources, **structuring brain research area**, reinforcing patient and public involvement and accelerating research transfer and innovation.

Please describe some of the current collaborative brain health initiatives in Europe

PA: Amongst European brain health collaboratives, there is a need to strengthen collaborations between each one and to work towards establishing a common brain health agenda. In the last ten years, both the European Commission (EC) and its Member States (MS) have established and led initiatives in Europe to face these challenges collectively. To date, there is JPND, the Joint Programming initiative on ND research, the largest global collaboration in this field/domain; NEURON – an EC ERANET partnership that supports basic,

clinical and translational research in the fields of brain diseases and the Human Brain Project – an EC's Future and Emerging Technologies Flagship funded by the seventh framework programme that aims to put in place a unique Information and Communications Technology-based infrastructure for brain research. In 2019, together with the European Brain Council, the three initiatives began discussions in the context of an EU-funded European Brain Research Area (EBRA) EC Coordination and Support Action, to discover operational synergies, identify strengths and gaps and foster alignment across European and global brain initiatives.

European Brain Research Area

In February 2022, EBRA released its long-awaited European Research Inventory and Mapping Report, providing insight into the brain research activities that are funded at the European level within the EU framework programmes FP7 and Horizon 2020 (the Framework Programme for Research and Innovation (2014-2020) under the ERA-Net Cofund programme), as well as the funding initiatives of JPND, ERA-NET NEURON and the Human Brain Project. The mapping report gives an overview of the current state of brain research in Europe and the areas of brain research (if any) that are being focussed in Europe. The report shows that, in spite of increased support in brain research, funding is still lacking in all areas of brain research in the EU. For instance, more focus is needed on public and patient engagement and on enabling data sharing.

From 2007 to 2019, the EC and leading European brain research initiatives allocated €6 billion to about 4,000 brain research projects, an average of €500 million per year. From 2008 to 2012, an average of 400 million was invested per year, increasing between 2014 to 2018 to 550 million, marking a steady growth. *"The EBRA inventory and mapping report demonstrates that annual fundings can reach significant levels to support highly competitive research projects especially through sustainable, transnational initiatives as JPND."* – Philippe Amouyel

However, continued funding of research consortia across countries is key for a lasting impact on collaboration and innovation in the European and global brain research area. *"It is now time to accelerate this momentum through an ambitious partnership on brain health in Horizon Europe under a coordinated approach."* – Philippe Amouyel

JPND and Patient and Public Involvement

Another crucial component in JPND's move towards stronger brain health partnerships is to foster greater public and patient involvement (PPI) in brain health research. JPND has been calling for heightened awareness in the need to incorporate PPI in ND and brain health research. There is an overt call for the strategic implementation of PPI in JPND's annual calls, the encouragement of active PPI participation in all of JPND-supported projects, the training of public, patients and patient advocates, the running of workshops emphasising PPI, the acculturation of scientists and physicians to PPI and a dedicated PPI page on JPND's website to increase awareness of the important role PPI plays in brain health research.

JPND's goal toward a stronger brain health partnership

PA: Creating a critical mass of researchers and increased funding are two of the conditions of success in our work against brain diseases. As one of EBRA's partners, we are committed to a future partnership on brain health in the 2nd strategic programme of Horizon Europe 2025. Only by working together collectively: bringing together all brain research initiatives under one umbrella; coordinating brain research activities under a common brain research agenda, will we be able to make progress in the face of tackling the challenges posed by ND and brain diseases.

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The EU Joint Programme – Neurodegenerative Disease Research (JPND)

JPND – finding cures for neurodegenerative diseases and working to enable early diagnosis for early targeted treatments with worldwide collaboration.

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