

ERA-NET Neuron

# NEWSLETTER 24



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## News From NEURON II

**The first Joint Transnational Call (JTC) of ERA-NET NEURON Cofund on “External Insults to the Nervous system” was launched and the deadline for sending preproposals was March 14th, 2016.**

**The next workshop of ERA-NET NEURON Cofund will be on NEUROETHICS and will be held in Milan, May 2016, followed by the meeting of Neuron’s Network Steering Committee.**

## From the desk of the coordinator | March 2016



Marlies Dorlöchter

**The 2015 movie ‘Concussion’ shows dramatically how external insults to the nervous system can lead to neurological deterioration with a broad spectrum of symptoms and severe disabilities. Sport activities, traffic accidents and violent encounters often cause traumatic brain and spinal cord injuries.**

These are in the focus of the new funding initiative that the ERA-NET NEURON started right in the beginning of the year 2016 with the launch of a joint transnational call for (January 11th, 2016). NEURON partners from 18 countries and the European Commission allocated more than 20 million euros to fund research projects on these devastating conditions. The Lancet Neurology commented on this funding activity in its March issue (TNL 15, 231, 2016, [http://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(16\)00026-0/fulltext?rss=yes](http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(16)00026-0/fulltext?rss=yes))



More information can be found on our website  
<http://www.neuron-eranet.eu/index.php>  
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Another highlight in January was the NEURON symposium **'How to reinforce the interactions between scientists, clinicians and the society in the field of brain research?'** held in Berlin. Leading European neurologists, psychiatrists and neuroscientists as well as representatives of patient organisations met to discuss how to improve research collaboration between clinicians and basic scientists and how to involve patients in research activities.



Martin Dichgans

The symposium was opened by **Martin Dichgans** - chair of NEURON's scientific advisory board - with a 'General overview on the Strategic Research Agenda' (SRA) of the ERA-NET NEURON. He explained this framework for future investment to improve prevention, diagnosis, and treatment of diseases affecting the brain. Recommendations from the SRA will set the stage for the type and topics of the future joint calls and other activities of the ERA-NET.

As it turned out during the following presentations, there is broad agreement that the traditional divisions between the faculties of neurology and psychiatry and clinical and fundamental neuroscience are becoming outdated by the latest research findings. Once the brain and nervous system in their normal function are better understood, it will be easier to unravel their related disorders. Furthermore, since neurological and mental disorders can be conceptualized as disorders of the brain, both psychiatrists and neurologists need comprehensive training and continuing education in neurosciences and in each other's clinical fields. Here lies one of the challenges for universities, research institutions and funding organizations.



The speakers at the symposium



*Attending the symposium*

The symposium also emphasized the increasing awareness of patient involvement in brain research. Various models were suggested on what is the most appropriate type of patients' participation. For instance, patient organizations can be key partners in clinical trials. There is however a need to educate patients and scientists on why patient involvement in research is necessary and how it can be done. Such efforts should be directed towards the current lack of experience, education and awareness of both patient and lay organizations on the one hand and scientists and clinicians on the other hand. Practical benefits of successful involvement range from patient-friendly information sheets, better recruitment, and better dissemination of research results.

This newsletter is dedicated to the symposium and summarizes the main ideas presented by the speakers.

**Marlies Dorlöchter.**



## Symposium: How to reinforce the interactions between scientists, clinicians and the society in the field of brain research?

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### Foreword by the Symposium Chairs

#### **Etienne Hirsch**

Institut Neurosciences, Sciences Cognitives, Neurologie, Psychiatrie de l'INSERM, Paris, France

#### **Bernard Poulain**

Institut des Sciences Biologiques, Centre National de la Recherche Scientifique (CNRS), Paris, France



Etienne Hirsch



Bernard Poulain



Promoting a dialogue between researchers, practitioners and patients represents an important goal of NEURON Cofund. This is crucial for disseminating information about brain research, and it will allow collecting and discussing the needs of patients and their families and will help to shape research to more accurately address them. A first step in reaching this objective has been to organize on January 12, 2016 in Berlin a workshop bringing together representatives of international lay organizations and umbrella organizations such as European Federation of European societies for neurosciences, European Academy of Neurology, European Psychiatric Association, European Federation of Neurological Associations, Global Alliance of Mental Illness Advocacy networks (GAMIAN Europe), and others with NEURON partner organisations and members of the Scientific Advisory Board.

The outcome of this workshop will feed into measures supporting the efforts of the patient organizations to improve the lives of their members. One concrete measure, for instance, is the identification of several major needs of patients and their translation into scientific questions that will lead to solutions developed through NEURON-funded research projects. Another option could be organizing activities towards raising awareness of severe medical conditions in 'family conferences' in NEURON partner countries.

## Links between the professional communities: from bench to bedside

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Monica DiLuca



### The Point of View of the Neuroscientists

#### Monica DiLuca

President, Federation of European Neuroscience Societies (FENS),  
Vice-Rector for Internalization, University of Milan,  
Milan, Italy

Brain research in Europe is a rapidly evolving field and increasingly at the forefront of science. The complexity of understanding physiological brain functions and brain diseases brings responsibilities as well as opportunities for the neuroscience community: responsibility to develop novel tools and approaches in order to integrate and advance our understanding of the still unknown basic functions of the nervous system; opportunities to provide a better understanding of the underlying pathogenic mechanisms, to generate novel therapeutic approaches, thus confronting with a major societal challenge in Europe and worldwide.

The European Brain Council, with input from many societies including FENS, quantified the 'cost and burden' of major brain diseases in Europe, amounting to about 800 billion euro per year. The study also estimated that 179 million people of all ages had a brain disorder in 2010. The magnitude of these figures cannot be ignored and reflects an unquestionable level of emergency.

Considering the costs of brain diseases for the European society, and that these costs will increase considerably in the coming years due to the ageing of the European population, one way of curbing this increase and eventually decreasing the burden is through intensified research. It is, therefore, important to focus our efforts on basic as well as in clinical neuroscience research. Only by improving the insight in the basic functioning of the brain and translate this knowledge to the disease condition, by understanding the causes of the disease process, by paving the way for better targeted and improved treatment, the upwards spiral of the costs of brain disorders can be stopped. This is one of the focal areas of FENS and the field in which many European neuroscientists excel.

Günther  
Deuschl

## The point of view of the neurologists

### **Günther Deuschl**

President of the European Academy of Neurology,  
Chairman of the Department of Neurology,  
Christian-Albrechts University, Kiel, Germany

The European Academy of Neurology represents more than 20.000 neurologists in Europe and has the purpose to promote Excellence in Neurology in Europe. The two most important goals in this context are to 'support neurological research' and to 'increase the availability and standards of neurological services'. In this context the development of European guidelines for the treatment of neurological diseases are of very high importance.

In order to reach the goals we need to closely collaborate with basic neuroscience in the fields of molecular biology and systems biology. The aim is to develop an intense interaction to elaborate translational therapies. In addition, the phenotyping methodologies of basic research are of particular interest for neurology. The final goal of all such research developments is to develop treatment that needs to be assessed in pilot and large-scale trials.

Patient organisations are important to improve research questions that are meaningful to the patients and to adjust clinical research protocols to the latest developments. Patient organisations are very important to lobby for research resources at the European Commission and to collaborate in convincing politicians to improve the health systems in the European countries.

It is only the three components of stakeholders, namely: basic researchers, neurologists and patients, that can significantly forward the care of neurological patients.

Wolfgang  
Gaebel

## The Point of View of the Psychiatrists

### Wolfgang Gaebel

President, European Psychiatric Association; Director, Department of Psychiatry and Psychotherapy, LVR-Klinikum Düsseldorf, Clinics of the Heinrich Heine University, Düsseldorf, Germany

Psychiatry is a dynamically developing medical and scientific specialty with a biopsychosocial perception of mental disorders. Mental disorders require a multi-perspective approach in clinical practice and research, neurobiology is an essential element of it, but developing and evaluating innovative models of treatment and care are also important. Recent reviews, such as the European ROAMER project and the SRA developed by ERANET NEURON II, offer directions for brain research, psychiatry and mental healthcare. Beyond brain research, mental healthcare needs further development using evidence-based scientific and technological advances. Compared to research funding for the healthcare of somatic disorders, research in mental disorders is underfunded when the disability-adjusted life years (DALY) caused by somatic vs. mental disorders are taken as a standard to assess the relative funding levels in these two areas of healthcare. A comprehensive and integrated mental health research agenda should be expected to contribute to optimized treatment, care and functional outcome of patients with mental disorders. A significant element of fostering interactions between clinicians, scientists, patients and society at large is the joint development of recommendations for research directions. The European Psychiatric Association provides a forum for such developments. An important area of collaboration may be the elucidation of causes and consequences of the stigmatization of people with mental disorders. Neurobiological conceptions are necessary but will not suffice to reduce the stigmatization of mental disorders and may even increase them. Research programs are necessary to identify the most efficient ways to inform the public about the diagnostic and treatment opportunities provided by psychiatry. Neurosciences and lay organizations may support these approaches. Additional studies in social sciences are necessary to elucidate the interrelations between stigmatizing attitudes, funding allocations and research agendas.



## Links between basic scientists, clinicians and lay organizations

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Janine Blom



### Example of a Successful Collaboration between Funding Agencies, Researchers, Clinicians and Lay Organizations

**Janine Blom**, Programme officer, Translational Research, ZonMw, the Netherlands Organisation for Health Research and Development

**Martin Boer**, Director, Dutch Epilepsy Fund.  
The Hague, The Netherlands

End-user involvement has a distinct part within the ZonMw programme Translational Research and the Dutch Epilepsy Fund as well as in other 7 Health Funds.

End-users have a role in the assessment procedure and applicants of research grants are obliged to involve end-users in their project application, more than just as subjects in the study, otherwise they have to justify why this does not apply for their application. Panels of end-users assess the applications on their relevance for the patients. The panels' participants are with higher education and capable of understanding project proposals and most of them had previous experience in reviewing research projects. ZonMw organised a training course for patients' panels that was attended by most of the panel members.

Involving patient is not difficult to organise and it helps to make better choices in projects that are being funded. Because questions like: are patients' needs met, are there risks for patients, how time consuming and invasive is the project for patients and are privacy issues and ethics are considered thoroughly, cannot be answered solely by a scientific board and patients input is required. One has to make sure, however, that the questions one wants the patients to answer are addressed in the lay-term summary of the project that is written in the national language as reading the whole project proposal in English is needlessly time consuming may lead to misunderstanding.

The assessment of the end-user panel as well as the scientific committee is used for the final ranking of the applications in which the judgment of the panel carries more weight than the quality assessment of the committee.

The additional costs and time of the review process when end-users are included have to be taken into account. In order to achieve the highest possible benefit, it is necessary to train the applicants, scientific reviewers and end-users. We advise to utilize the available knowledge in the field of end-user participation, do not try to reinvent the wheel. And collaboration with organizations with access to end-users, such as patient organisations and umbrella patient organisations is highly recommended. Concluding from ZonMw experience, stakeholder and end-user involvement works, leads to new insights, better quality of research projects and needs of the end-users are better met.



Martin Boer







Donna  
Walsh



## How Can the Lay Organizations in the Field of Neurology Work with the Basic Scientists and the Clinicians to Fight Neurological Disorders

**Donna Walsh**

Executive Director, European Federation of Neurological Associations,  
Dublin, Ireland

Across the EU, there is diversity on whether Patient-Public Involvement [PPI] is required to secure national government/charitable funding. This presentation aimed to highlight that whether it is mandatory or not and despite the challenges, PPI is ultimately beneficial to all stakeholders. However, patients and the scientific community need to be educated on why PPI in research is necessary and how it can be done. National/European funders of research should provide guidance on the appropriate engagement of patients in different types of research, and support the development of national/European support services to assist researchers in this engagement. Additionally, patient organisations were presented as an obvious first point of contact and conduit between patients and researchers. Many such organisations already provide training and run capacity building initiatives for patient advocates and other stakeholders. So a pool of 'experts', from which researchers can select patient partners to be involved in the entire R&D process and beyond, is being created. The presentation explored why PPI in the field of neuroscience/neurology is more important than in other disease areas as, here, the most impactful symptoms and disease progress often cannot be directly measured (must be assessed using questionnaires or interviews with patients), secondary symptoms often more burdensome than primary. Therefore, the clinical scales by which outcomes can be measured are limited. The presentation finished with an exploration of how all stakeholders in the field should collaborate beyond the R&D phase to ensure that policy/decision-makers allocate resources proportionate to the burden of neurological disorders and provide access for patients to the best treatment/management tools available.



Raluca  
NICA



## How Can Lay Organizations in the Field of Psychiatry Work With the Basic Scientists and the Clinicians to Fight Psychiatric Disorders?

### **Raluca NICA**

Chair, Research Committee, GAMIAN Europe,  
Romanian League for Mental Health,  
Bucharest, Romania

GAMIAN Europe (Global Alliance of Mental Illness Advocacy Networks- Europe) is a patient-driven pan-European organization that represents the interests of individuals affected by mental illness and advocates for their rights.

GAMIAN have developed a network that includes 49 European organizations dealing with various mental disorders and thus allows GAMIAN Europe to present itself as a true Pan-European Advocacy organization operating across the whole spectrum of Mental Illnesses. Since 2010 GAMIAN Europe is actively involved in the Interest Group on Mental Health, Well Being and Brain diseases of the European Parliament and have produced position papers on European policy developments to ensure that the patients' voice is heard and taken into account when policies are developed.

The scientific research led to an increased knowledge on the neural substrates for the cognitive and effective functions that are disturbed in psychiatric disorders, allowing for a more comprehensive database on the biological basis of psychiatric illness and the generation of hypotheses to be tested. At the same time, psychiatrists are better prepared to diagnose mental illness, estimate their risk based on genetic information and predict treatment response.

GAMIAN Europe considers that there are considerable opportunities to conduct research on the causes of mental illness in order to determine when, where, and how to intervene and to develop mental health treatments and approaches responsive to diverse needs and circumstances linked to the patients.

In this respect, GAMIAN Europe supports the development of further research as cooperation between basic scientists, clinicians, researchers and patients, as it considers that this development is essential for patients not only to reduce their psychiatric symptoms but also to better integrate in the society and have an increased quality of life.



Hervé  
Chneiweiss



## Ethical aspects of patients and professionals relationships

### **Hervé Chneiweiss**

Head, Neuroscience Paris Seine - IBPS laboratory, Sorbonne Universités, UPMC Univ Paris, Centre National de la Recherche Scientifique (CNRS), Institut National de la Santé et de la Recherche Médicale (INSERM), Paris France

Because of the overwhelming need for treatments and interventions addressing diseases of the brain; because new knowledge in neuroscience feeds public/media/politicians imagination about possible brain manipulation; because some innovative practices such as the general use of screening may change the architecture of our brain; because novel knowledge in neuroscience may change our approaches to education, moral judgment, decision-making, but also obesity, diabetes, addictions: Ensuring public faith in neurosciences and novel neuro-technologies blooming from our discoveries, is crucial. This will require collaborative public engagement activities involving both researchers and clinicians, coupled with strong governed procedures and effective regulation. Durable integration of neuroscience with the Ethical, Legal and Socio-cultural/humanities (ELSA) disciplines e.g. by including interdisciplinary ELSA teams directly into neuroscience projects, would be beneficial. This may result in harmonization of professional guidelines pertaining ethical management of the data/material, management of incidental findings in neuroscience and preventing conflicts of interest. Open discussions are also needed to improve informed consent in neuroscience and neurotechnologies, to face controversies such as the use of animal in neuroscience, and promote scientific integrity. To do so we should open our scientific meetings to some special sessions for ELSA discussions for questions or suggestions from the lay public.



## Brain research policies

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Mary G  
Baker



### How to Speak to Politicians to engage countries in the fight for prevention of Brain Disorders

**Mary G Baker**

Immediate Past President of the European Brain Council

Brain research in Europe is a rapidly evolving field. The complexity of understanding brain function and brain diseases brings responsibilities as well as opportunities for the neuroscience community for the benefit of society. Despite these major challenges and all the efforts of the scientific community in Europe, we are still struggling against the discrepancy, still present in Europe, between the huge societal impact of brain diseases on the one hand, and the modest financial and time resources allocated for brain research, teaching and the care of brain diseases on the other. There is no way to escape from the fact that brain disorders are a major public health problem in Europe and the rest of the world. An analysis of the health economic studies of brain diseases in Europe, published by the European Brain Council in 2011, led to an estimate of €798 billion for the total cost of brain disease in Europe in 2010. This burden is bound to grow. Addressing these large costs requires intensified research, both basic and clinical, and the creation of novel solutions. Future generations deserve nothing less.

We must also understand the policies and the active outlines presented by the various directorates of the Commission and work to use the aspirations of each Presidential term of each Country to benefit society. We must work with the policy makers.

The combination of ageing populations and lower economic growth is leading policy makers to question the sustainability of European healthcare expenditure.

At the same time as seeking to increase 'cost-effectiveness', however, we must also strengthen our focus on the outcomes our health systems deliver - for the patient, the economy, and society.



Catherine Berens



## Facts about Brain Research in Europe and Future Politics

### Catherine Berens

Head of Sector Neuroscience, European Commission, DG Research & Innovation  
E4 Non-communicable diseases and the challenge of healthy ageing

Brain research is a priority for the European Union. During the course of the EU FP7 (2007–2013), an unprecedented level of more than €3 billion was allocated to support basic, translational and clinical research and healthcare assessment on brain functions and processes, neurodegenerative diseases and other neurological diseases, neuropsychiatric diseases, rare diseases of neurological origin, as well as public health research.

Horizon 2020, the EU Framework Programme for Research and Innovation (2014–2020), couples research to innovation, covering all forms of innovation from research to new products and services. In this frame, Horizon 2020 offers many opportunities for support to brain research and innovation.

Collaborative research on brain and brain diseases is mainly supported under the 'Health, demographic change and wellbeing societal challenge (SC1). SC1 adopts a challenge-driven approach, with broad, less prescriptive topics and a stronger focus on end-users, including patients, compared to FP7. The horizontal nature of this societal challenge ensures cross-fertilisation of disciplines and approaches across the entire spectrum of the health innovation chain. The budget of the first Horizon 2020 brain collaborative projects exceeds €350 million. The 2016–2017 'Personalised medicine' call for proposals offers additional opportunities.

The Innovative Medicines Initiative (IMI) 2, the public-private partnership between the EU and pharmaceutical industry, will contribute significantly to developing next generation medicines and treatments for neurodegenerative and psychiatric diseases.

Horizon 2020 also supports the coordination of national research efforts on brain research through the Joint Programming Initiative on Neurodegenerative Diseases Research (JPND) and the European Research Area Network NEURON.

The European Union contributes to strengthen brain international cooperation, for instance via the International Initiative for Traumatic Brain Injury Research (InTBIR), or the Human Brain Project (HBP). Other opportunities for research on brain and brain diseases also exist in other parts of Horizon 2020 (e.g. under the 'Excellent science' and 'Industrial leadership' Horizon 2020 priorities).

Stakeholders of brain research are hence encouraged to seize the opportunities offered under Horizon 2020 in order to advance knowledge on brain and brain diseases for the benefit of citizens and healthcare systems.