



Expanding brain research in Europe – A societal need?

Brain Awareness Week – Outreach Event

16 March 2017

European Parliament (SDM-S7), Strasbourg

**#ILoveMyBrain
#BrainAwarenessWeek**



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■ AGENDA

08:30 – 09:00 Registration

09:00 – 09:15 Welcome address by host Ms Anne Sander, MEP.

Introduction by moderator, Mr Frédéric Destrebecq, Executive Director of the European Brain Council (EBC)

Brain Awareness Week background, Prof. Roland Pochet, Belgian Brain Council

09:15 – 09:30 Prof. Marion Leboyer, The Mondor Institute of Biomedical Research (IMRB, Inserm U955 – University Paris Est Créteil, UPEC)

Supporting research in psychiatry in Europe: A major societal issue

09:30 – 09:45 Ms Joke Jaarsma, European Federation of Neurological Associations (EFNA) & European Alliance for Restless Legs Syndrome (EARLS)

Putting neurology patients at the heart of research

09:45 – 10:00 Prof. Monica di Luca, European Brain Council (EBC) & Federation of European Neuroscience Societies (FENS)

Brain Research in Europe: Our Challenge for the Future

10:00 – 10:50 Contributions from the audience and general discussion

10:50 – 11:00 Closing remarks by host Mr Momchil Nekov, MEP

11:00 – 11:30 Coffee reception

■ EBC - Who we are

The European Brain Council (EBC) is a non-profit organization gathering patient associations, major brain-related societies as well as industries. Established in March 2002, its mission is to promote brain research in order to improve the quality of life of those living with brain disorders in Europe. 165 million Europeans are living with a brain disorder, causing a global cost (direct and indirect) exceeding 800 billion euros for the National Health budgets. EBC's main action areas are:

- Fostering cooperation with its member organizations
- Promoting dialogue between scientists, industry and society
- Interacting with the European Commission, the European Parliament and other relevant international institutions
- Raising awareness and promoting education on the brain
- Disseminating information about brain research and brain diseases in Europe

Through this workshop, EBC and all partner organizations, aim to:

- Highlight the growing societal need to expand brain research in Europe, and provide an open forum for policymakers and the general public to understand the reasons why.
- Create a forum for discussion with all stakeholders involved in order to raise awareness and create ways of collaboration, as well as encouragement for all sides to act.
- Promote the recognition of brain disorders as social and economic burdens, and that the expansion of brain research is vital.
- Start a conversation and work in alignment with the EU institutions relevant to health and research.
- Raise public awareness of the prevalence of brain disorders, and the burdens they place on society as a whole.



■ Brain Awareness Week



The global campaign to increase public awareness of the progress and benefits of brain research

Brain Awareness Week unites the efforts of partner organizations from around the world in a weeklong celebration of the brain every March. Partners organize creative and innovative activities in their communities to educate and excite people of all ages about the brain and the promise of brain research.

Brain Awareness Week was founded in 1996 by the Dana Alliance for Brain Initiatives. FENS joined the celebrations in 2006, administering the grants that the Dana Foundation reserves for participating European organisations.



Happening now

This year FENS and the Dana Foundation supported 36 projects in 23 countries: Armenia, Bosnia and Herzegovina, Croatia, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Netherlands, Poland, Portugal, Romania, Russia, Serbia, Spain, Switzerland, Turkey, Ukraine and United Kingdom.

Brain Awareness Week in Budapest focuses on the roles of 'playing and gaming' in the functioning of the brain. Workstations comprise a giant playground, where the audience can run experiments on rodents as they play and exercise, and can carry out human psycho-physiological exercises.



The Institute for Biomedical Research in Madrid invites 14-16 year-old students to observe the brain via their mobile phones.

The University of Cambridge is hosting BRAINArt, a Brain Art competition and exhibition involving students (aged 8-18). It is part of the Cambridge BRAINFest, the biggest local outreach event for neuroscience in Cambridge in years.

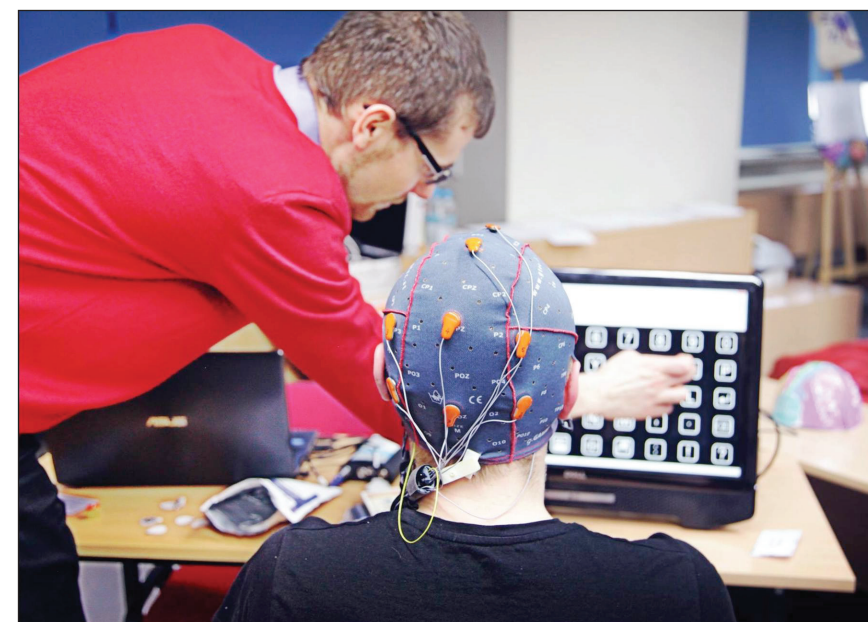
Quotes:

"Now in its 22nd year, Brain Awareness Week continues to flourish because of participation of partners from around the globe, like FENS, and their commitment to educating the public about the importance of brain research and its critical role in helping people lead healthier, more productive lives." - Edward Rover, Chairman, The Dana Foundation & The European Dana Alliance.

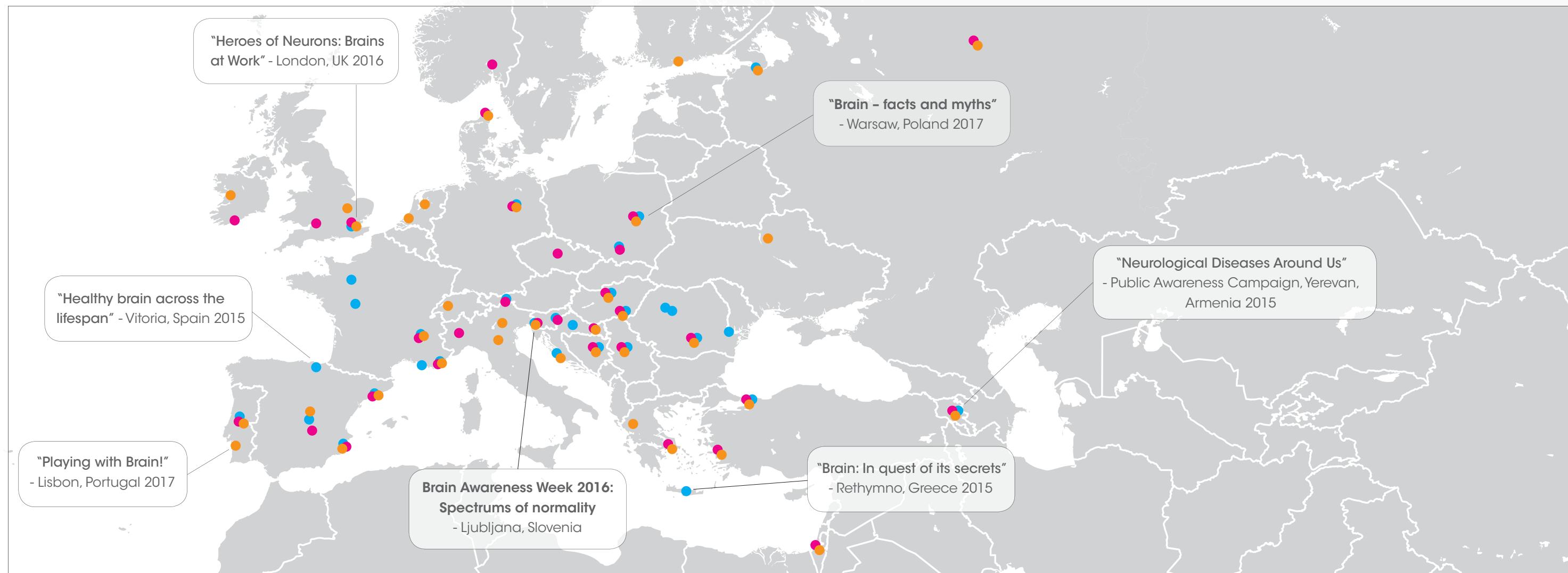
"We at FENS enthusiastically support the many innovative initiatives of the Brain Awareness Week that help communicate scientific breakthroughs to European citizens and to spark the interest of potential future neuroscientists. Brain Awareness Week is of primary importance in enabling the public understanding and transparency of brain research." - Barry Everitt, FENS President.

"Our society has organised Brain Awareness Week events since 2006. We always get enthusiastic feedback. The activities help forge direct communication between neuroscientists and the public, and many misconceptions regarding brain function, neuropsychiatric disorders and their treatment have been countered in this way." - The Hellenic Society for Neuroscience (Greece).

www.fens.org/Outreach/FENS-Brain-Awareness-Week/



Brain Awareness Week - Past and Current Events



2015

Armenia / Yerevan
Austria / Innsbruck
Bosnia and Herzegovina / Tuzla
Croatia / Osijek
France / Valbonne, Jouy-en-Josas (Paris), La Tronche, Nouzilly (Tours)
Germany / Berlin
Greece / Rethymno
Hungary / Szeged, Budapest
Italy / Trieste
Poland / Krakow, Warsaw
Portugal / Coimbra
Romania / Braila, Cluj-Napoca, Bucharest
Russia / St. Petersburg
Serbia / Belgrade
Slovenia / Ljubljana
Spain / Barcelona, Sant Joan d'Alacant, Vitoria, Ciudad Real
Turkey / Kocaeli/Istanbul
United Kingdom / London

2016

Armenia / Yerevan
Austria / Innsbruck
Bosnia and Herzegovina / Tuzla
Croatia / Zagreb, Zadar
Czech Republic / Hradec Kralove/Prague, Libechov
Denmark / Aalborg/Aarhus
France / La tronche/Grenoble, Valbonne (French Riviera), Marseille
Germany / Berlin
Greece / Amorgos island, Athens, Patras, Peloponnese, Salonika-Greece
Hungary / Szeged, Budapest
Ireland / Cork
Israel / Haifa
Italy / Torino, Trieste
Norway / Oslo
Poland / Krakow, Warsaw
Portugal / Lisbon, Coimbra
Romania / Bucharest
Russia / Perm
Serbia / Belgrade
Slovenia / Ljubljana
Spain / Sant Joan d'Alacant, Toledo, Bellaterra
Turkey / Kocaeli, Izmir
United Kingdom / Bristol, London

2017

Armenia / Yerevan
Bosnia and Herzegovina / Tuzla
Croatia / Osijek, Zadar
Denmark / Aalborg Øst
Finland / Helsinki
France / Grenoble, Valbonne (French Riviera)
Germany / Berlin
Greece / Athens, Patras, Pyrgos, Amorgos, Nafpaktos in Greece, Ioannina
Hungary / Szeged, Budapest
Ireland / Galway
Israel / Jerusalem
Italy / Trieste, Verona, Reggio Emilia
Netherlands / Amsterdam
Poland / Warsaw
Portugal / Lisboa, Coimbra
Romania / Bucharest
Russia / Perm, St.-Petersburg
Serbia / Belgrade
Spain / Barcelona, Sant Joan d'Alacant, Madrid
Switzerland / Vaumarcus/Neuchâtel
Turkey / Gebze, Izmir
Ukraine / Kyiv
United Kingdom / Denmark Hill (London), Cambridge

■ Biographies



Host Anne Sander has been a French Member of European Parliament (MEP) since 2014. She is part of the European People's Party (Christian Democrats), and sits on the Committee on Employment and Social Affairs and the Delegation for relations with Japan, and a substitute for the Committee on Industry, Research and Energy.

@ASanderMEP



Host Momchil Nekov has been a Bulgarian Member of European Parliament (MEP) since 2014. He is part of the Group of the Progressive Alliance of Socialists and Democrats in the European Parliament, and sits on the Committee on Culture and Education and the Delegation for relations with the People's Republic of China.

@MomchilNekov



Host Ms Frédérique Ries, MEP is a Belgian politician and has been a Member of the European Parliament for Belgium since 1999 as part of the Alliance of Liberals and Democrats for Europe (ALDE). She is a member of the Committee on the Environment, Public Health and Food Safety (ENVI).



Organizer Roland Pochet, PhD, honorary Professor of Cell Biology at the Faculty of Medecine de l'Université Libre de Bruxelles, is a neuroscientist whose main topic is stem cell transplantation on a rat model for Amyotrophic Lateral Sclerosis. He is currently the Secretary-General of the Belgian Brain Council, a National Brain Council made up of 25 patients associations, 14 scientific societies and 25 pharmaceutical companies. He was an evaluator for the European Commission of FP7 Regpot (Regional potential) projects, is a member of the European Dana Alliance for the Brain and sits on the board of the Bureau Alsace-Europe in Brussels.

@rpochet54



Moderator Frédéric Destrebecq has been the Executive Director of the European Brain Council since October 2014. Prior to this position, he served at the European Union of Medical Specialists (UEMS) as Chief Executive Officer, and previously as Director for European Affairs. Frédéric holds a Master Degree in Political Science and International Relations from the Université Catholique de Louvain (Belgium). He also studied at the Institut d'Etudes Politiques (Paris) and University of Wales College(Cardiff), in the framework of the former EU Socrates exchange programme.

@BrusselsDC



Speaker Marion Leboyer, M.D., Ph.D. is currently Professor of Psychiatry at the University of Paris Est (UPEC) in France, head of the University-affiliated department of Psychiatry and Addiction (Hôpitaux Universitaires Mondor, Assistance-Publique-Hôpitaux de Paris) and also runs the laboratory "Translational Psychiatry" belonging to INSERM (Paris). Her research efforts have contributed to a better identification of genetic and environmental risk factors in major psychiatric disorders. In order to better understand the causes of mental disorders, she has been able to produce prominent findings such as identification in autism of the first mutations of genes implicated in synaptogenesis and is now implicated in several programs focusing on immune dysfunctions observed in psychiatric disorders.



Speaker Joke Jaarsma became active in patient advocacy for restless legs syndrome (RLS) in the late 1990's. After ten years of RLS work in her home country, The Netherlands, she started the European RLS Alliance in 2009. To date, Joke is past president of the European Alliance for Restless Legs Syndrome (EARLS), and has broadened her outlook to advocacy for all neurological illnesses. She is Secretary General of the European Federation of Neurological Associations (EFNA), and patient representative on the Board of the European Brain Council and on the Education Committee of the European Academy of Neurology. Joke has also spent most of her working life as publisher of scientific journals, books and databases.

@joke_jaarsma



Speaker Monica DiLuca is Professor of Pharmacology at the University of Milano. Her primary research interest is related to synaptic plasticity in physiological and pathological conditions, with the primary aim to apply basic findings to the cure of neurodegenerative diseases such as Alzheimer's and Parkinson's Disease. She has been member of Council of several national and international scientific organizations including Federation of European Neuroscience Societies (FENS, Past President), European Brain Council (EBC, current Vice President) and the International Brain Research Organization (IBRO) and the European Dana Alliance for the Brain (EDAB).



■ Speakers abstracts

Marion Leboyer – *Supporting research in psychiatry in Europe: A major societal issue*

Mental disorders represent the single greatest economic and social burden on European society. The cost of mental disorders (excluding dementia and other organic brain disorders) in 2010 was estimated at €461 billion. This is the lowest current estimate for this figure, as it does not take into account the large additional costs associated with having co-occurring mental and physical disorders.

With sufficient investment, mental health research could address the burdens in Europe, especially through research on prevention of mental disorders in young or at-risk populations, on improvement of understanding of causes, on developing new tools for diagnosis and innovative therapeutic strategies, thus promoting positive mental health in the general population. Such approaches have been advocated by the European Parliament and the European Commission, and Prof. Leboyer will outline the most pressing mental health research that takes advantage of Europe's infrastructure and research strengths, including the EU ROAMER project.

Joke Jaarsma – *Putting neurology patients at the heart of research*

Patients should be involved in helping to shape priorities for research that is ultimately carried out for their benefit. A growing body of evidence suggests that involving patients in research improves the relevance, quality and speed of that research. Furthermore, including patients as top level priorities in order to close the gap between what researchers want to research and what patients want researching is likely to be beneficial for all research.

The Value of Treatment project initiated by the European Brain Council is one excellent example of patient participation in research. The project addresses the burden of disease and the issues in the current healthcare system, and proposes evidence-based and cost-effective solutions to achieve high value for patients. By describing ("mapping") the patient journey in full detail (by both patients and health care professionals), treatment gaps have been identified which will be addressed in the policy recommendations resulting from this project.

Monica DiLuca – *Brain Research in Europe: Our Challenge for the Future*

Brain diseases represent a considerable social and economic burden in Europe. With yearly costs of about 800 billion euros and an estimated 179 million people afflicted in 2010, brain diseases are an unquestionable emergency and a grand challenge for neuroscientists. Considering the costs of brain diseases for the European society, and considering that these costs will increase considerably in the coming years due to the ageing European population, one way of curbing this increase and possibly decreasing the costs is via intensified research. Thus, strong basic research in neuroscience and the development of a strong European platform for neuroscience is needed to face brain diseases, which nowadays represent a societal emergency in European countries.

■ Partner Organizations



The European Dana Alliance for the Brain (EDAB) has a mission to make information on the brain accessible and understandable to the general public, involving them in the excitement and importance of progress in research. There are over 280 EDAB members, from 33 European countries, who are recognised for their Brain Awareness Week (BAW) outreach efforts and other projects throughout the year.

www.dana.org

@dana_fdn



The Belgian Brain Council unites Belgian scientific organizations of neuroscientists, psychiatrists and research workers, patients' associations and pharmaceutical companies with the goals to improve the treatment for persons with neurological and psychiatric diseases, make people more aware of this subject, stimulate research and exchange between the different disciplines and associations, and lobby for enhancing the funding of research and treatments.

www.belgianbraincouncil.be



FENS, the Federation of European Neuroscience Societies, is the main voice of European neuroscience, representing close to 23,000 European neuroscientists from over 30 European countries. FENS promotes excellence in neuroscience research and neuroscience research to policy-makers, funding bodies and the general public, both regionally and internationally, and facilitates the exchange between neuroscientists within the European Research Area and beyond.

www.fens.org

@FENSorg



EPA, the European Psychiatric Association, deals with psychiatry and its related disciplines with a focus on the improvement of care for the mentally ill as well as on the development of professional excellence. Representing over 78,000 European psychiatrists, EPA is the main association representing psychiatry in Europe.

www.europsy.net

@Euro_Psychiatry



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@EUneurology



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