Expanding brain research in Europe
Education, Behaviour and Brain Development

Brain Awareness Week – Outreach Event

15 March 2018
European Parliament (Room LOW N3.3), Strasbourg

#ILoveMyBrain
#BAW2018
SUMMARY

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**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.

**AGENDA**

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<th>Time</th>
<th>Event</th>
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<tr>
<td>08:30 – 09:00</td>
<td>Registration</td>
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<tr>
<td>09:00 – 09:15</td>
<td>Welcome address by hosts Ms Anne Sander &amp; Ms Daciana Sârbu, MEPs</td>
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<td>Introduction of the European Brain Council by Prof. Monica Di Luca,</td>
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<td>EBC President &amp; Ms Joke Jaarsma, EBC Treasurer</td>
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<td>Introduction of Brain Awareness Week by Prof. Roland Pochet,</td>
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<td>EBC-BBC Liaison Officer</td>
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<td>09:15 – 09:30</td>
<td>Professor Albert Gjedde, Professor of Neurobiology and Pharmacology</td>
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<td>at the Faculty of Health Sciences and Department of Neuroscience at</td>
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<td>the University of Copenhagen, Denmark</td>
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<td>The predictive brain</td>
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<td>The future: How to boldly go where no one has gone before</td>
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<td>09:30 – 09:45</td>
<td>Prof. Steven Laureys, Director, Coma Science Group at the University</td>
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<td>and University Hospital of Liège, Belgium</td>
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<td>Brain, Coma, and (Un)consciousness</td>
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<td>09:45 – 10:00</td>
<td>Prof. Gaia Novarino, Assistant Professor and head the Novarino Group</td>
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<td>at the Institute of Science and Technology, Austria</td>
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<td>How to find treatments for pediatric neurological disorders?</td>
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<td>10:00 – 10:50</td>
<td>Contributions from the audience and general discussion moderated</td>
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<td>by Prof. Patrice Boyer, EBC Vice-President</td>
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<td>10:50 – 11:00</td>
<td>Closing remarks by host Ms Lieve Wierinck, MEP</td>
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<td>11:00 – 11:30</td>
<td>Coffee reception</td>
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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 have supported 35 projects in 22 countries: Armenia, Belgium, Croatia, Denmark, Estonia, France, Germany, Greece, Hungary, Ireland, Italy, Poland, Portugal, Romania, Russia, Serbia, Slovenia, Spain, Switzerland, Turkey, Ukraine and United Kingdom.

“Brain and Society: the world is changing... and our brain?” encompasses activities throughout the Provence-Alpes region of France focusing on the brain’s remarkable potential for adaptability.

In Greece, the Hellenic Society for Neuroscience is organising a series of events throughout the country during Brain Awareness Week, including public talks, laboratory exhibitions, theatrical plays about brain processes and neuropsychiatric disorders, musical events and interactive constructions regarding the brain and its functions.

The Open Science Hub-Portugal in Barca d’Alva focuses on how to understand human behaviour through research by inviting rural communities in Portugal to create, design and manipulate the brain of artificial creatures.

“Now in its 23rd 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

“The Bernstein Center for Computational Neuroscience Berlin (BCCN Berlin) will present a poster on their activities at the Brain Awareness Week Corner of the FENS Forum 2018 held in Berlin, July 7-11. www.fens.org/2018

www.fens.org/Outreach/FENS-Brain-Awareness-Week/
Brain Awareness Week - Past and Current Events

2016
- Armenia / Yerevan
- Austria / Innsbruck
- Bosnia and Herzegovina / Tuzla
- Croatia / Zagreb, Zadar
- Czech Republic / Brno, Hradec Kralove/Prague, Liberec
- 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 / Lisbon, 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

2018
- Armenia / Yerevan
- Belgium / Leuven
- Croatia / Zadar
- Denmark / Aalborg Øst
- Estonia / Tallin
- France / French Riviera
- Germany / Berlin
- Greece / Athens
- Hungary / Budapest
- Ireland / Galway
- Italy / Torino
- Poland / Krakow
- Portugal / Coimbra
- Romania / Bucharest
- Russia / St.-Petersburg
- Serbia / Belgrade
- Slovenia / Ljubljana
- Spain / Barcelona
- Switzerland / Basel
- Turkey / Gebze
- Ukraine / Kyiv
Biographies

Host Anne Sander has been a French Member of the European Parliament (MEP) since 2014. She is part of the European People’s Party (Christian Democrats) and sits on the European Parliament’s Committee on Economic and Monetary Affairs (ECON). She is also a substitute in the Committee on Employment and Social Affairs (EMPL).

@ASanderMEP

Host Daciana Sarbu has been a Romanian Member of the European Parliament (MEP) since 2007. She is part of the Group of the Progressive Alliance of Socialists and Democrats (S&D) and is Vice-Chair of the Committee on the Environment, Public Health and Food Safety (ENVI). She is co-chair of the MEP Interest Group on Brain, Mind, and Pain, an initiative of the European Federation of Neurological Associations (EFNA) and Pain Alliance Europe, whose aim is to explore issues of common interest to those affected by neurological and chronic pain disorders, including stigma, quality of life, research and patient involvement.

@DacianaSarbu

Host Lieve Wierinck has been a Belgian Member of the European Parliament (MEP) since 2016. She is part of the Group of the Alliance of Liberals and Democrats for Europe (ALDE) and sits in the Committee on Industry, Research and Energy (ITRE). Ms. Wierinck has a background in Pharmacy and worked as a Pharmacist for almost 30 years before becoming an MEP.

@LieveWierinck

Moderator Monica Di Luca is the President of the European Brain Council and Professor of Pharmacology, Vice - Rector for International Strategies, Director of NeuroNest (Center of Neuroscience) and Head of Laboratory of Pharmacology of Neurodegeneration – DiSFeB 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), the International Brain Research Organization (IBRO) and the European Dana Alliance for the Brain (EDAB).

@EU_Brain

Moderator Joke Jaarsma is the Treasurer of the European Brain Council. Joke is past president of the European Alliance for Restless Legs Syndrome (EARLS), and has broadened her outlook to advocacy for all neurological illnesses. Joke Jaarsma is President of the European Alliance for Restless Legs Syndrome, Vice-President of the Dutch Restless Legs Patient Group and Member at Large of EFNA. She has suffered from severe Restless Legs for many years. In her working life, Joke was Publisher of scientific books and journals.

@joke_jaarsma

Speaker Professor Albert Gjedde is a Danish-Canadian neuroscientist. He is Emeritus Professor of Neurobiology and Pharmacology at the Faculty of Health Sciences and Department of Neuroscience at the University of Copenhagen. He is currently Professor of Translational Neurobiology at University of Southern Denmark; Adjunct Professor of Neurology and Neurosurgery in the Department of Neurology, Montreal Neurological Institute, McGill University, Canada; Adjunct Professor of Radiology and Radiological Science in the Division of Nuclear Medicine, Department of Radiology and Radiological Science, Johns Hopkins University, USA; and Adjunct Professor of Psychiatry at Tabriz University of Medical Sciences, Iran.

Prof. Gjedde’s research focuses on the relations between neuroplasticity and neurotransmission that can be revealed by mapping radioligand binding and the neuroplastic changes of brain functions. The investigations explore the relation between energy metabolism and neurotransmission by recording the changes of energy metabolism and consciousness under pharmacological and other manipulations. His collaborations focus on experiments with volunteer subjects and patients that explore the lesions and degeneration of brain tissue in disorders such as epilepsy, lusomania, Parkinson’s disease, stroke, depression, and somatizing disorders, as well as disorders related to addiction.

@agjedde

Speaker Prof. Steven Laureys MD PhD is director of the Coma Science Group at the GIGA Research and Neurology Department of the University and University Hospital of Liège, Belgium. He is Research Director at the Belgian National Fund for Scientific Research and board-certified in neurology and in end-of-life medicine. He is President of the Association for the Scientific Study of Consciousness and Chair of the World Federation of Neurology Applied Research Group on Coma. His team has an international reputation in the assessment of consciousness and patients come to his center in Liège from all over Europe for neuroimaging tests and medical expertise. His latest book, published by Academic Press, is entitled “The Neurology of Consciousness”.

@stevenlaureys

Speaker Gaia Novarino is a neuroscientist who investigates the genetic and molecular basis of neurodevelopmental disorders. Novarino studied Molecular Biology and received her Ph.D. in Cell Biology in 2006. After receiving training in modeling human disorders, employing both mouse and cellular models, Novarino began combining her experience in studying disease with her expertise in human genetics. Prof. Novarino joined IST Austria as Assistant Professor in 2014. Together with her team, her scientific work aims to identify and study genes underlying inherited forms of epilepsy, intellectual disability, and autism.

In 2016, Novarino was awarded an ERC Starting Grant, a Simons Foundation Autism Research Initiative Investigator Award, and a Boehringer Ingelheim FENS Research Award, and was appointed Kavli Scholar of the Federation of European Neuroscience Societies.
that do not. The main characteristic of life forms that have brains, such as animals, is their ability to move. A testable answer to the question is the claim that the ability of animals to move led to the evolution of brains. According to this key hypothesis, brains evolved ultimately to satisfy three essential needs of creatures that move, i.e., 1) to store the memories of past actions, 2) to be conscious of the present, and 3) to turn memories into conscious imaginations of the future. When people want to move, networks of cells in the brain use imaginations of the future to help individuals anticipate and choose the most salutary of actions. What then happens when brains age? It is my claim that failure of one or more of these three fundamental mechanisms explains the core symptoms of autism. Autism spectrum disorders are a group of conditions characterized by defects in social interaction and communication skills accompanied by the presence of stereotypic or repetitive behaviors. The core symptoms of autism are rarely isolated and most often coexist with other conditions such as mental retardation or epilepsy. Despite decades of intensive research, disorders such as autism and epilepsy remain poorly treatable. Moreover, novel drugs addressing the needs are far from sight and major pharmaceutical companies have retreated from the search for new drugs to treat neuropsychiatric disorders.

In the last years, researchers have found that autism spectrum disorders, epilepsy and mental retardation are often caused by tiny mistakes in the patient’s DNA, the blueprint of life which is found in all our cells. These mistakes, called mutations, change the shape of some essential miniscule machine parts of the brain, the proteins. Genetic information, therefore, may retain the key to reveal potential treatment options.

Discutant Roland Pochet Roland Pochet, PhD, honorary Professor of cell biology at the Faculty of Medicine at the Université Libre de Bruxelles (ULB) and a neuroscientist whose main topic is stem cell transplantation on a rat model for Amyotrophic Lateral Sclerosis. He is currently a member of the executive committee of the Belgian Brain Council. He was chairman (2002-2010) of the Biomedicine Domain of the international organisation COST, evaluator for the European Commission of FP7 Regpot (Regional potential) projects. Furthermore, he is member of EDAÉ (European Dana Alliance for the Brain) and sits on the board of the Bureau Europe Grand Est in Brussels.

@rpochet54

Prof. S. Laureys – Brain, Coma, and (Un)consciousness

Understanding consciousness remains one of the greatest mysteries for science to solve. How do our brains work? Will we ever be able to read minds? How can we know if some patients in coma have any consciousness left and how could we communicate with them? What are near-death experiences? What is brain death? What happens in our brains during dreaming, hypnosis or meditation? At present, nobody understands how matter (our trillions of neural connections) becomes perception and thought.

We will here briefly review some neurological facts on consciousness and impaired consciousness. While philosophers have pondered upon the mind-brain conundrum for millennia, scientists have only recently been able to explore the connection analytically through measurements and perturbations of the brain’s activity. This ability stems from recent advances in technology and especially from emerging functional neuroimaging and electrophysiology studies. The mapping of conscious perception and cognition in health (e.g., conscious waking, sleep, dreaming, hypnosis, meditation, sleepwalking and anesthesia) and in disease (e.g., coma, near-death, “vegetative” state, seizures, hallucinations etc.) is providing exiting new insights into the functional neuroanatomy of human consciousness. Our perception of the outside world (sensory awareness; what we see, hear, etc.) and our awareness of an inner world (self-awareness; the little “voice” inside that “speaks” to ourselves) seemingly depend on two separate networks we could recently identify.

Philosophers might argue that the subjective aspect of the mind will never be sufficiently accounted for by the objective methods of reductionistic science. We here prefer a more pragmatic approach and remain naively optimistic that technological advances might ultimately lead to an understanding of the neural substrate of human consciousness. We will conclude by discussing the ethical consequences of these scientific advances which offer the medical community unique ways to improve the clinical management and quality of life in patients with severe disorders of consciousness.

Discutant Patrice Boyer, MD, Ph.D is Vice-President of the European Brain Council and honorary professor of clinical neurosciences psychopathology and psychiatry at the University of Paris 7- Denis Diderot(France), professor of psychiatry (geographical) at the University of Ottawa, Ontario, Canada and professor of post graduate studies in the same University. On a European and international level Prof. Boyer is past president of the European Psychiatric Association (EPA) and past chairman of the ECNP networks Initiative (ENI) coordinating 6 research networks in Europe. Prof. Boyer is member of the EPA board and executive committee since June 2000 and of the EPA council of National Associations since January 2012.

@EU_Brain

Speakers abstracts

Prof. Albert Gjedde – The predictive brain - The future: How to boldly go where no one has gone before

Neuroscience has advanced greatly in recent years but the most fundamental questions remain unanswered. This includes the one question that may appear to be the easiest to answer at first sight: What are brains good for? When there are plenty of successful life forms that have no brains, a tentative answer must be sought in the difference between life forms that have brains and life forms that do not. The main characteristic of life forms that have brains, such as animals, is their ability to move. A testable answer to the question is the claim that the ability of animals to move led to the evolution of brains. According to this key hypothesis, brains evolved ultimately to satisfy three essential needs of creatures that move, i.e., 1) to store the memories of past actions, 2) to be conscious of the present, and 3) to turn memories into conscious imaginations of the future. People want to move, networks of cells in the brain use imaginations of the future to help individuals anticipate and choose the most salutary of actions. What then happens when brains age? It is my claim that failure of one or more of these three fundamental mechanisms explains the core symptoms of autism. Autism spectrum disorders are a group of conditions characterized by defects in social interaction and communication skills accompanied by the presence of stereotypic or repetitive behaviors. The core symptoms of autism are rarely isolated and most often coexist with other conditions such as mental retardation or epilepsy. Despite decades of intensive research, disorders such as autism and epilepsy remain poorly treatable. Moreover, novel drugs addressing the needs are far from sight and major pharmaceutical companies have retreated from the search for new drugs to treat neuropsychiatric disorders.

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Prof. Gaia Novarino – How to find treatments for pediatric neurological disorders?

Neurological disorders are a great burden to patients and their families as well as to society. Neu rodevelopmental disorders affect millions of individuals from very young ages, and are often refractory to treatments. For example, one in less than 100 children is diagnosed with an autism spectrum disorder. Autism spectrum disorders are a group of conditions characterized by defects in social interaction and communication skills accompanied by the presence of stereotypic or repetitive behaviors. The core symptoms of autism are rarely isolated and most often coexist with other conditions such as mental retardation or epilepsy. Despite decades of intensive research, disorders such as autism and epilepsy remain poorly treatable. Moreover, novel drugs addressing the needs are far from sight and major pharmaceutical companies have retreated from the search for new drugs to treat neuropsychiatric disorders.

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Partner Organizations

The Neuropôle de Strasbourg is a federation of 37 research teams hosted in 11 research units (CNRS, INSERM, University of Strasbourg, Hospital), working in various areas of fundamental and clinical neurosciences. It also includes technological platforms, various associations, industries and clinical services, all related to neurosciences. One strength of the Neuropôle de Strasbourg is a continuum of research from basics to clinical application in neurosciences aiming at responding to the societal demands and expectations in public health. Another particularity of the Neuropôle de Strasbourg is its very strong interaction with local European countries through the trans-national network Neurex, supporting university education and research in collaboration with the Neuroscience Federations of Basel and Fribourg.

www.neuropole.u-strasbg.fr

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

The Bureau Europe Grand Est, formally the Bureau Alsace, is the representation of the Grand Est Region in France (former Alsace, Lorraine, Champagne-Ardenne) local, regional authorities and consular bodies to the European Union in Brussels. The Office aims to make the voice of the region and regional actors to the European institutions to promote and support initiatives and projects of its partners from the European Union.

www.bureau-alsace.eu