



# **EBC** **ANNUAL** **REPORT** 2018

**IMPROVING  
BRAIN KNOWLEDGE  
AND ADVOCACY**

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# INTRODUCTION

By Monica Di Luca & Frédéric Destrebecq



A handwritten signature in black ink, appearing to read 'Monica Di Luca'.

Prof. Monica Di Luca  
*President*



A handwritten signature in black ink, appearing to read 'Frédéric Destrebecq'.

Frédéric Destrebecq  
*Executive Director*



Vision without action is merely a dream.  
Action without vision just passes the time.  
**Vision with action can change the world.**

*Joel A. Barker*

Dear Colleagues,

We are pleased to present to you our Annual Report of 2018.

This year's report sets a key milestone in EBC's communication and outreach, as it is the first in a fully electronic copy, in line with EBC's move into the "digital era". We very much hope that you will embrace this development and will appreciate this new format.

2018 marked the first year of work and collaboration of the EBC's current Executive and, more particularly, the establishment of a new strategic plan for the organization. This plan – articulated around three complimentary pillars: political, public and private outreach – was presented and supported by the Board of EBC and now serves as the backbone of EBC's operation. More recent developments in this regard, such as the creation of working groups and committees, will aim at fostering the way EBC engages with its members and partners but will also contribute to improve the outcomes of our action thanks to closer involvement and coordination.

This improved efficiency in our operation is key, particularly at a time when working closely with members and partners has never been so important. As a matter of fact, collaboration across our constituency has always been the central component in the way we as EBC operate; it was, nonetheless, necessary to foster it in a more dynamic way. With ongoing developments linked to the coordination of the "European Brain Research Area (EBRA)", the continued work on our "Value of Treatment" project, the launch of our "Value of Innovation" agenda and other initiatives, we need involvement from all in order to ensure that EBC fulfills its role. It is envisioned that, thanks to these developments, EBC will set itself again in future as the initiator and coordinator of further large-scale initiatives.

We look forward to this improvement in our efficiency as a key element to ascertain our position and visibility to the EU institutions. In 2018, again, our permanent contact with the European Commission and the European Parliament did contribute to maintain a strong focus on the importance of steady investment into brain research and improved brain health in Europe. This was particularly true with the proposal and negotiations for the forthcoming framework programme for research and innovation: "Horizon Europe".

We very much look forward to the continued collective success of EBC and its member organisations and societies – with and through the involvement of EBC's constituency.

# EBC MISSION & VISION



# EBC Mission

The European Brain Council (EBC) is a network of key players in the “Brain Area”, with a membership encompassing scientific societies, patient organisations, professional societies and industry partners.

## EBC strives for a world where:

- The brain is recognized as our most valuable asset
- No stigma is associated with brain diseases
- Prevention, early diagnosis and treatment of brain diseases and research of the brain is prioritized by society

## EBC realizes this through:

- Policy and advocacy work alongside awareness raising
- Encouraging prevention & treatment
- Stimulating innovation

A non-profit organisation based in Brussels, our main mission – by bringing together science & society – is to promote brain research with the ultimate goal of improving the lives of the estimated 179 million Europeans living with brain conditions, mental and neurological alike.





# Research & Innovation Agenda

## Political Agenda

The human brain is an indispensable organ, as it regulates our emotions, thoughts, feelings, speech, movement and shapes our habits and personalities. However, the brain is also extremely vulnerable, which is why brain conditions can severely impact a person's cognitive abilities, social skills and overall quality of life. What is more, the complexity of the human brain makes it difficult to fully understand mental and neurological conditions. As of yet, despite the tremendous social and economic impact of brain disorders, there is no disease-modifying treatment available to cure a wide range of brain-related diseases.

EBC and its member societies are convinced that strong action at a Europe-wide scale is key to enhancing the understanding of the brain and accelerating the development of effective remedies. As such, EBC has launched a wide range of advocacy initiatives throughout 2018 aimed at transforming the EU into a global hub for brain research and a birthplace of novel treatments for improving the quality of life of people living with brain conditions.

June 2018 marked the publication of the proposals for the 9<sup>th</sup> EU Framework Programme for Research and Innovation, entitled "Horizon Europe". This programme will fund science across the EU during 2021-2027. The European Commission proposed an indicative budget of €94.1 billion. Within this budget, €7.7 billion is allocated to the "Health Cluster" under Pillar II "Global Challenges and Industrial Competitiveness". What is more, against the backdrop of the recommendations provided by the Lamy-report, the Commission proposed a mission-oriented approach that allows the EU to set a limited number of inspirational, measurable, ambitious and time-bound targets that should be achieved by means of the Framework Programme.

EBC strongly believes that a robust Framework Programme could significantly accelerate brain research and has called on the European Parliament, Commission and national governments to make more funding available for health research and introduce further targets and objectives aimed at addressing the societal burden caused by brain disorders.

In light of the above, EBC has actively engaged with key EU officials in order to make them aware of the impact of brain disorders as well as how Horizon Europe can address the societal challenges presented by these conditions. In particular, the meetings that were held with former Director General of DG RTD Mr. Robert-Jan Smits as well as Ms. Giulia Del Brenna and Mr. Alfredo Sousa within the cabinet of Commissioner Carlos Moedas constitute key highlights in these endeavours. Furthermore, EBC reached out to national governments, highlighting the importance of a robust Horizon Europe programme, prior to the Council meetings that were held on 17<sup>th</sup> July and 15<sup>th</sup> October.



On the occasion of the event “Brain Research in Europe: Shaping FP9 and Delivering Innovation to the Benefit of Patients” that was held on 23<sup>rd</sup>-24<sup>th</sup> April 2018, EBC launched its “Brain Mission” statement, **“Understand - Fix - Enhance: The Space Race of the 21<sup>st</sup> Century”**, amongst the presence of the newly appointed Director General of DG RTD Jean-Eric Paquet. This document, written by leading brain researchers and scientists, provides guidance to decision-makers on how to design a brain mission.

The workshop addressed various issues that affect the development of new treatments that could benefit patients living with mental and neurological conditions. Developing such treatments is extremely challenging due to the relatively high risk of clinical failure, increased drug development costs and low approval rates in the domain of Central Nervous System (CNS) disorders. The workshop welcomed insight from various representatives of patients, brain researchers, payors, clinicians, regulators and industries, who shared their perspectives on how to accelerate therapeutic innovation in this field.

In line with EBC’s advocacy in the domain of therapeutic innovation, various activities were launched in 2018 in order to further promote the Declaration on Good Off-Label Use Practices (GOLUP). This declaration calls on regulators and decision-makers to adopt guidelines on the practice of off-label use of medicines in Europe and address issues connected to innovation, patient safety and professional liability. The workshop on “The use of off-label medicines in Spain”, that was organized on 25<sup>th</sup> April 2018 in Madrid, in cooperation with the Spanish Brain Council, constitutes a key milestone in these efforts.

Furthermore, in order to raise awareness about the need for a robust Horizon Europe budget, EBC launched the statement “Counting down to zero: Towards a future with under-funded health research?”. This statement, supported by 32 healthcare stakeholders across disciplines and disease areas, called on the EU institutions to increase the overall budget of Horizon Europe to at least €120 billion. Decision-makers are urged to allocate more funding to the “Health Cluster” as health was previously allocated 12% under the 7<sup>th</sup> Framework Programme, 10% under Horizon 2020 and 8% in the proposed Horizon Europe budget.

EBC responded to a call for feedback on the Horizon Europe proposals that was launched by the European Commission. In its response, EBC underlined, amongst other issues, the need to adopt a mission on the brain as well as a robust “Health Cluster”. The feedback EBC provided highlighted that brain research should be included amongst the priorities of the «Non-Communicable and Rare Diseases» area.

# Research & Innovation Agenda

On the national level, EBC reached out to its membership and network of National Brain Councils (NBCs) in order to share the news about the call for feedback, which led to FENS, EFNA, EAN as well as 11 NBCs and national partners providing input underlining the importance of making Horizon Europe a key milestone in progressing brain research. 8 NBCs also wrote to national decision-makers echoing the feedback that they submitted to the official call for feedback.

EBC's advocacy on Horizon Europe has been central to many meetings organized during the second half of 2018. On the occasion of the EBC Strategic Workshop, held on 24<sup>th</sup>-25<sup>th</sup> September 2018, Deputy Director-General of the European Commission Directorate-General for Research and Innovation (DG RTD), Wolfgang Bartscher, shared his perspective on the proposed structure of Horizon Europe.

EBC also organized the networking reception "Uncorking the Brain" on 21<sup>st</sup> November 2018, bringing together EBC's membership, and prominent scientists as guest speakers to exchange views on EBC's brain mission statement and their views on the future of brain research and the funding of brain research in the EU.



THE EUROPEAN BRAIN COUNCIL PRESENTS

**BRAIN MISSION**  
**UNDERSTAND - FIX - ENHANCE**  
THE SPACE RACE OF THE 21<sup>ST</sup> CENTURY



OUR MISSION IS TO  
PROMOTE BRAIN  
RESEARCH WITH  
THE ULTIMATE GOAL  
OF IMPROVING  
THE LIVES OF THE  
ESTIMATED 179  
MILLION EUROPEANS  
LIVING WITH BRAIN  
CONDITIONS,  
MENTAL AND  
NEUROLOGICAL  
ALIKE.



# EBC HIGHLIGHTS OF 2018



# Brain Awareness Week 2018

Brain Awareness Week (BAW), an initiative by the Dana Foundation, is the global campaign to increase public awareness of the progress and benefits of brain research. Every March, BAW unites the efforts of partner organizations worldwide in a celebration of the brain for people of all ages.

To mark this year's Brain Awareness Week, EBC held its annual awareness event, "**Expanding Brain Research in Europe: Education, Behaviour and Brain Development**", for policymakers and the general public within the European Parliament in Strasbourg, in partnership with the Federation of European Neuroscience Societies (FENS), the European Dana Alliance for the Brain, the Belgian Brain Council, the University of Strasbourg-Neuropole and the Bureau Grand Est.

The event was co-hosted by MEPs Anne Sander (France, EPP), Daciana Sârbu (Romania, S&D), and Lieve Wierinck (Belgium, ALDE) and co-moderated by EBC President Prof. Monica Di Luca and EBC Treasurer Ms Joke Jaarsma.

Prof. Albert Gjedde of the University of Copenhagen spoke on "The predictive brain and the future: to boldly go where no one has gone before", which explored how the most fundamental questions about the brain still remain unanswered despite the great advances in neuroscience over the recent years.

Prof. Steven Laureys, Director of the Coma Science Group at the GIGA Research and Neurology Department of the University and University Hospital of Liège, Belgium, spoke freely to the room on his work in consciousness and coma science, and how understanding consciousness remains one of the greatest mysteries for science to solve. He also made the case for continued but starker support from the EU institutions for science and research, asking for continuity in funding and the work being done – breaking free from project-based restraints, allowing for consistency and longer-term research.

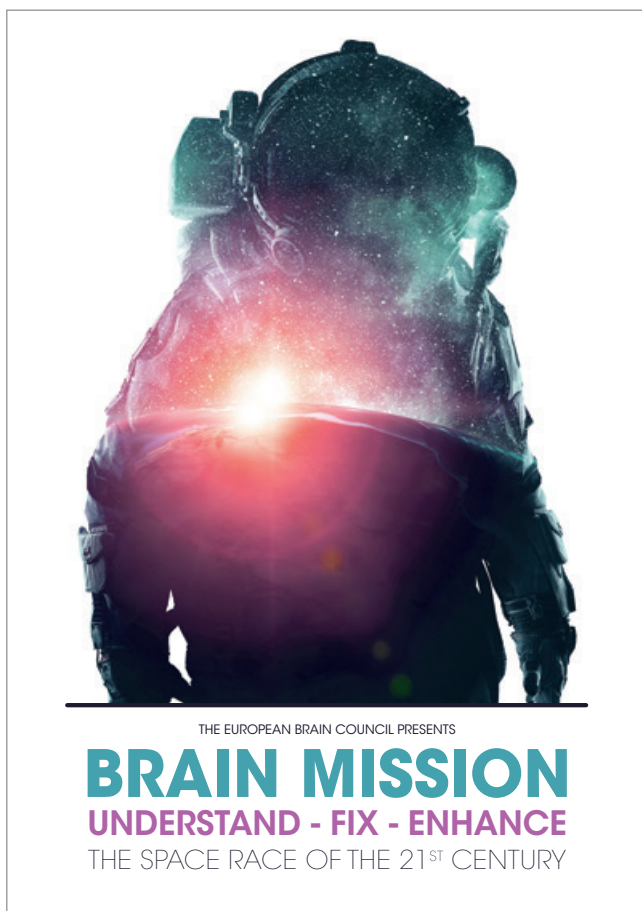
Prof. Gaia Novarino, a neuroscientist who investigates the genetic and molecular basis of neurodevelopmental disorders at IST Austria, spoke on how scientists work to find treatments for pediatric neurological disorders. Neurodevelopmental disorders affect millions of individuals from very young ages, are often refractory to treatments and, despite decades of intensive research, disorders such as autism and epilepsy remain poorly treatable.





## Brain Mission & 'Counting Down to Zero' Statement

On 23<sup>rd</sup> April 2018, the European Brain Council launched its "Brain Mission"—a call to action for Europe and its policymakers to recognize the brain as a territory still in need of exploration. In 2018, the European Commission proposed for a mission-oriented and impact-focused 9<sup>th</sup> Framework Programme, entitled Horizon Europe. In view of this, the European Brain Council's Brain Mission aims to bring attention to brain research and brain conditions, to present how the post-2020 Framework Programme can make a real difference for patients living with brain disorders.



With the burden of brain disorders continuously growing, the target of our proposed Brain Mission was to decrease this enormous burden through better understanding of the physiology of the brain and disease states, relevant prevention strategies, as well as more generally, an increased awareness of the brain and its diseases.



# "Brain Research in Europe: *Shaping FP9 and Delivering Innovation to the Benefit of Patients*" Event



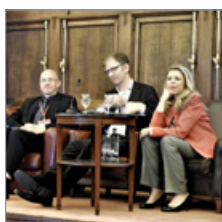
The EBC Brain Mission was launched on the occasion of the EBC event "Brain Research in Europe: Shaping FP9 and Delivering Innovation to the Benefit of Patients".

The two-day event was held on 23<sup>rd</sup>-24<sup>th</sup> April and was organised into three different sessions: "**FP9 and Missions**", "**The Value of Innovation**" and "**European Brain Research: Shifting Gears and Going Global**". The event aimed to bring together leading healthcare stakeholders and policymakers to address key questions in the domain of research, such as how the upcoming 9<sup>th</sup> Framework Programme can accelerate brain research across

Europe, what measures can be taken in order to stimulate the development of new central nervous system drugs for treating brain disorders, and what can be done to address the concerns of patients.

Then newly appointed Director-General of the European Commission Directorate-General for Research and Innovation, **Jean-Eric Paquet**, was able to join the event and addressed the audience, giving insight into what's ahead as the work to shape the next Framework Programme began, speculating on how a mission-oriented approach could pan out.

Other speakers included Keynote Speaker **Prof. Andrea Renda**, exploring EU research as it stands now, and the session on "The Value of Innovation" aimed to empower healthcare experts and stakeholders to present their views on issues that hinder therapeutic innovation and discuss potential solutions, with a panel discussion bringing together various stakeholders from Association Internationale de la Mutualité, European Observatory on Health Systems and Policies, the European Federation of Pharmaceutical Industries and Associations (EFPIA), Alliance for Biomedical Research in Europe and the European Commission Directorate-General for Health and Food Safety (DG SANTE).



The third session drew focus to global initiatives and the potentials to increase collaboration at the international level, aiming to provide an overview of the current global brain research initiatives and to allow experts to present their perspectives on how to further enhance cooperation at global level. This brought together speakers from the **Human Brain Project**, **ERA-NET Neuron**, the **EU Joint Programme – Neurodegenerative Disease Research (JPND)**, **International League Against Epilepsy (ILAE)**, **International Neuroinformatics Coordinating Facility (INCF)** and **International Initiative for Traumatic Brain Injury Research (IntBIR)**.

# The Value of Innovation Series Event: “Enhanced engagement through public-private partnerships”

On 21<sup>st</sup> November 2018, EBC held one of its largest events to date as part of its Value of Innovation series. The event, **“Enhanced engagement through public-private partnerships: sustaining therapeutic innovation to address patient needs”**, was an excellent showcase of the latest initiatives of EBC members and partners to key stakeholders, highlighting collaboration, innovation and multi-stakeholder engagement.

Built around a number of keynote speeches, presentations and poster presentations, the aim for the day was to create a forum and foster dialogue focused on improving outcomes for patients in 3 key areas – Research & Development in Brain Health, Patient Engagement and Disease Awareness.

EBC was pleased to welcome two keynote speakers, **Ms Sohini Chowdhury, Deputy CEO of the Michael J. Fox Foundation for Parkinson’s Research** and **Prof. Guendalina Graffigna from Università Cattolica Milan**, as well as chairs **Dr. Pierre Meulien, Director of the Innovative Medicines Initiative (IMI)** and **Mr Andrew Powrie-Smith, Executive Director of Communications & Partnerships at European Federation of Pharmaceutical Industries and Associations (EFPIA)** and EBC executives.



The day featured six presentations on R&D Breakthroughs in Brain Health, three presentations on Engaging Patients in Their Care and fifteen poster presentations, covering topics such as PET-MR, digital therapeutics, disease-specific treatment developments, patient empowerment, engagement and outreach projects, as well as disease awareness initiatives.

**Sohini Chowdhury**, Deputy CEO of the Michael J. Fox Foundation, highlighted the importance of the private sector in improving outcomes for brain health during her Keynote







*Prof. Guendalina Graffigna delivers Keynote on engaging patients in their care*



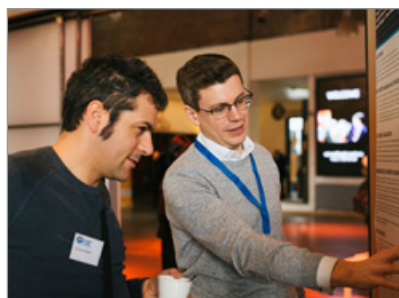
*Panelists **Andy Powrie-Smith** (EFPIA), **Prof. Eero Castren** (FENS), **Joke Jaarsma** (EBC & EFNA) and Moderator, **Donna Walsh** (EFNA)*



*EBC President, **Prof. Monica Di Luca**, gives the concluding remarks; Patient Engagement session ongoing*



*EBC Executive Director, **Frédéric Destrebecq**, summarizes the audience feedback received during the interactive session*



*Lunchtime Poster Session fully underway, with 14 posters all showcasing disease awareness initiatives.*

# PROJECTS & INITIATIVES





# EU-Funded Projects: The European Brain Research Area (EBRA)



1 November 2018 marked the launch of the European Brain Council (EBC)-coordinated EU project The European Brain Research Area (EBRA). EBRA was designed to respond to the Horizon 2020 call, SC1-HCO-10-2018, entitled “Coordinating European brain research and developing global initiatives”, which called for the reduction of fragmentation and duplication of research efforts, fostering synergies through enhanced coordination of brain research efforts at EU and at global level.

The European Brain Research Area project — EBRA — was created as a catalysing platform for brain research stakeholders (researchers, clinicians, patients, governments, funders and public institutions) to streamline and better co-ordinate brain research across Europe while fostering global initiatives.

The Consortium consists of the EBC membership, the Network of European funding for Neuroscience research (NEURON), Joint Programme – Neurodegenerative Disease Research (JPND) and the Human Brain Project (HBP).

Over the next three years, the EBRA Consortium will work to foster alignment and better coordination of research strategies across European and global brain initiatives; facilitate the emergence of research projects in specific areas in active clusters, and provide them with support for effective collaboration, including enabling sharing of data and access to research infrastructures and increase the visibility of the brain research portfolio as a whole and promote the uptake of EBRA results to key stakeholders.



*EBRA Kick-off meeting,  
1<sup>st</sup> November 2018,  
Brussels, Belgium*



The EBRA project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement N° 825348.

# EU-Funded Projects: MULTI-ACT

## More impact of health research on people with brain diseases



The MULTI-ACT project started on the 1<sup>st</sup> of May 2018 and will continue for three years. It has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Grant Agreement No. 787570.

The EU-funded MULTI-ACT project addresses the need to foster innovation by building effective collaboration along the research and innovation process, with the involvement of all stakeholders, including academia, government and regulatory agencies, patient and health foundations, biotechnological companies and pharmaceutical industries. MULTI-ACT aims to increase the impact of health research on people with brain diseases and it will create and implement a new model allowing for the effective cooperation of all relevant stakeholders. This will be applicable in defining the scope of health research as well as new metrics for the evaluation of its results. MULTI-ACT works with patients and patient organizations, academics, private and public stakeholders to develop brand new tools to assess the value of research and to ensure the sustainability of multi-stakeholder research initiatives.

EBC is deeply involved in the MULTI-ACT project as it aligns with its strategic objectives of patient engagement and improvement of research impact. EBC leads 3 work packages which entail the implementation of the MULTI-ACT model and tools to a selected research initiative in Multiple Sclerosis, the scale up of the model and tools to research initiatives in other brain disease areas, and finally, the communication and dissemination of the projects results.



*MULTI-ACT  
Kick-off meeting,  
14<sup>th</sup>-15<sup>th</sup> May 2018,  
Genova, Italy*



This project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Grant Agreement N°. 787570



## EU-Funded Projects: AD Detect-Prevent

Further to EBC's advocacy and work on digital health, EBC became part of the "AD Detect and Prevent" consortium. This EU-funded project, funded under the EU's Horizon 2020 programme and coordinated by the digital therapeutics company Brain+, aims to develop an innovative digital healthcare tool for identifying subtle cognitive signs associated with Alzheimer's disease (AD) before the possible onset of dementia.

Personalized and tailored intervention schemes will subsequently be offered. Furthermore, the project will work to exploit the synergies of its cross-disciplinary consortium of patient organisations, start-ups and academics, to effectively address this issue. As such, the "AD Detect and Prevent" digital tool, to be launched in Denmark and the UK by 2020, holds a tremendous potential for enhancing the discovery of AD at an early stage and lowering the addressable risk of developing dementia.

The kick-off meeting was held on 23<sup>rd</sup> November 2018. During the coming two years, EBC will support the outreach activities that will be launched within the framework of the project as well as the dissemination of key milestones and deliverables.

## EU-Funded Projects: ASCTN-Training

Neuronal disorders (NDs) are associated with behavioural and cognitive impairments and have a high prevalence. As such, they place a high financial and social burden on patients and their social network.

To reduce the impact of NDs, new scientific technologies and disease models must be developed and specialized professionals are needed. The primary aim of ASCTN-Training is to provide the appropriate training for participating Early Stage Researchers (ESRs) so each individual ESR will complete a PhD degree based on their research work, while simultaneously equipping them with the necessary tools to collaborate and develop innovative technologies for the modelling of NDs and the development of novel therapies.

EBC will take part in the organization of a workshop entitled "Bridging science, policy and society" and provide participating ESRs with inter-disciplinary training on the role of science in policy-making. The workshop aims to introduce them to the European science policy-making process, to empower them with ways to become a voice for neuroscience research throughout their careers and to explore potential career opportunities in science policy and advocacy.

# EBC PROJECTS



# Value of Treatment

## Dissemination

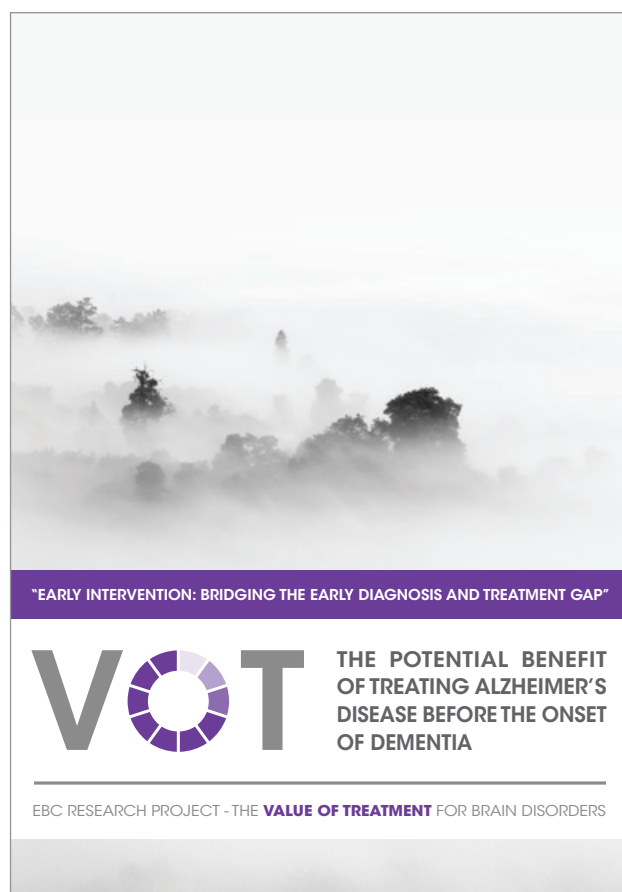
On 25<sup>th</sup> of September, EBC held an event in the European Parliament on the Value of Treatment's work on Alzheimer's Disease and the socioeconomic impact of Alzheimer's in Europe. This event was an opportunity to further present the EBC Value of Treatment project, particularly the work and findings of the Alzheimer's Disease working group.

The event was hosted by MEPs Heinz K. Becker (EPP, AT) and Marian Harkin (ALDE, IE), both members of the European Alzheimer's Alliance, moderated by Geoff Meade and chaired by EBC President, Prof. Monica Di Luca.

Dr. Ron Handels and Prof. Philip Scheltens, members of the VoT Alzheimer's Working Group, presented their work on the potential health-economic impact of treating Alzheimer's and the patient journey for people living with Alzheimer's. Mr Nis Peter Nissen then continued with a national insight, speaking on the cost of informal care of Alzheimer's in Denmark.

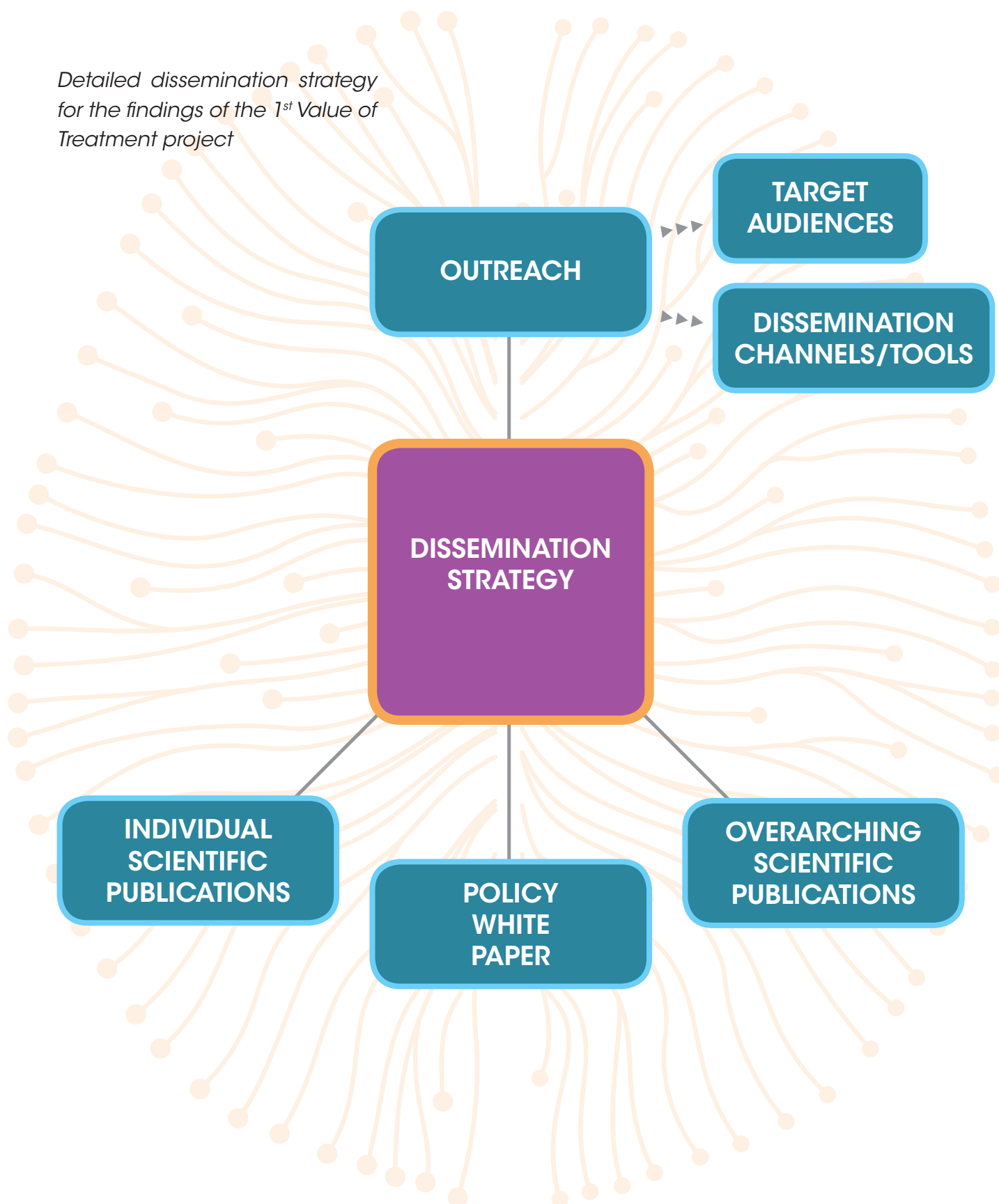
The roundtable brought together key stakeholders in the Alzheimer's and neurology communities, including leading academic and policy experts on the socioeconomic burden of Alzheimer's from organisations such as the OECD and the European Commission.

The event also served as the launch for an additional Value of Treatment booklet, focused specifically on showcasing the findings of the Alzheimer's working group and the potential benefit of treating Alzheimer's Disease before the onset of dementia.



## Value of Treatment

*Detailed dissemination strategy  
for the findings of the 1<sup>st</sup> Value of  
Treatment project*





# THE VALUE OF TREATMENT: EARLY INTERVENTION TO REDUCE THE BURDEN OF BRAIN DISORDERS

By: David Nutt, Patrice Boyer, Monica Di Luca, Wolfgang Oertel, Frederic Destrebecq, Vinciane Quoidbach, and Giovanni Esposito



David Nutt is President at the European Brain Council (EBC), Brussels, Belgium and the Edmond J. Safra Professor of Neuropsychopharmacology and director of the Neuropsychopharmacology Unit in the Division of Brain Sciences at Imperial College London, UK; Patrice Boyer is Vice President at the EBC, and Honorary Professor of Neuroscience and Psychiatry at Paris 7 University, France; Monica Di Luca is Vice President at the EBC and Professor of Neuropsychopharmacology at University of Milan, Italy; Wolfgang Oertel is Treasurer at the EBC Hertie Senior Research Professor and Professor of Neurology at Philipps-Universität Marburg, Germany; Frederic Destrebecq Executive Director at EBC; and Vinciane Quoidbach and Giovanni Esposito are Research Project Managers at EBC.  
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**Summary:** Direct health care and the non-medical costs of brain disorders make up 60% of the total costs associated with brain disorders, and are estimated at €800 billion per year in Europe. As prevalence and incidence are increasing for most mental and neurological disorders, we will need to manage several important challenges to achieve more value-based and patient-centred research and care. The health care sector in Europe is currently characterised by fragmented services for these conditions. The European Brain Council's recent report highlights the need for early, if possible prodromal, diagnosis and intervention; integrated, seamless care underpinning timely care pathways; and access to the best treatments available.

**Keywords:** Brain Disorders, Treatment Gaps, Value-based Care, Patient-centred Care, Early Intervention

## Introduction

According to various large-scale studies conducted by the World Health Organization, about a third of the population worldwide have a mental disorder. Taken together with neurological disorders, these "disorders of the brain" account for 23% of the global disease burden. This surpasses both cardiovascular diseases (5%) and cancer (10%).

Such statistics may be surprising as there is a general lack of awareness regarding the pervasiveness of brain disorders. However, global data, and particularly those on the European Union (EU), can serve as a wake-up call. Brain disorders are major contributors to morbidity,

disability and premature mortality in Europe. Highly prevalent, they currently affect 179 million people (an estimated 38.2% of the EU population) annually, with a peak in early adulthood (between 20 and 30 years) for mental and substance abuse disorders compared to neurological disorders, where DALYs (Disability-Adjusted Life Years) are more constant across age groups.

The prevalence of brain disorders is growing due to the so-called epidemiological transition from acute to chronic diseases and the increase in life expectancy, but also because of a number of socio-economic, environmental and behavioural health determinants,

### Towards earlier diagnosis and treatment of disorders of the brain

Monica Di Luca,<sup>a</sup> David Nutt,<sup>b</sup> Wolfgang Oertel,<sup>b</sup> Patrice Boyer,<sup>b</sup> Joke Jaarsma,<sup>b</sup> Frederic Destrebecq,<sup>b</sup> Giovanni Esposito<sup>b</sup> & Vinciane Quoidbach<sup>b</sup>

The 2015 Global Burden of Disease study estimates that about a third of the population worldwide is affected by mental or neurological disorders across their lifespans.<sup>1</sup> This high burden<sup>2,3</sup> may be surprising as there is a general lack of awareness on the pervasiveness of disorders of the brain. Global data, but particularly those from European studies, indicate that these disorders are a major public health problem: disorders of the brain rank among the leading causes of ill-health and disability and account for 35% of Europe's total disease burden with a yearly cost of 800 billion euros, of which 60% are related to direct health care and non-medical costs.<sup>4,5</sup> The burden is growing due to the epidemiological transition from acute to chronic diseases and the increase in life expectancy, but also because of several socioeconomic, environmental and behavioural health determinants.

Mental and neurological disorders are complex and are linked to hundreds of specific diagnoses.<sup>6,7</sup> The causes of such disorders are heterogeneous, ranging from pathological protein aggregation leading to neurodegeneration or dysregulation of the immune process, to developmental and functional abnormalities. These disorders also frequently involve an intricate interplay between genetic and environmental factors. Needs for basic and clinical research, the provision of medicines and medical devices, and adequate health-care systems and services are growing, but are increasingly unmet.

Discussions on health care focus too often on the increase of health-care cost rather than on the benefits of better health. Therefore, emphasizing on the need for more value-based and patient-centred care, and for the scaling-up of an integrated care model for mental and neurological disorders is important. An integrated care model encompasses the whole care process, from prodromal, early diagnosis to disease management and patient empowerment.<sup>8</sup>

The European Brain Council, an organization promoting research in Europe on health and disorders of the brain to improve the quality of life of those living with such disorders, initiated a two-year research project on the value of treatment. The project included case studies on schizophrenia, Alzheimer disease, epilepsy, headache, normal pressure hydrocephalus, Parkinson disease, multiple sclerosis, restless legs syndrome and stroke. The study's research framework included the testing of an integrated model and the development of a series of qualitative and quantitative benchmarks to identify treatment gaps and causal factors along the continuum of care in a patient care pathway analysis. The study also estimated the socioeconomic impact and health gains from best practice health-care interventions with an economic evaluation. Case studies were analysed in collaboration with hundreds of experts from the European Brain Council in line with the research framework, applying empirical evidence from different European countries.

In June 2017, the council published the outcome of these case studies in *The value of treatment for brain disorders – policy white paper*.<sup>9</sup> The publication provides important new insights into recent progress in the areas of pharmacology and the biopsychosocial approach, and into health-care service delivery and integrated care for brain disorders. Conclusions link early detection and diagnosis of disease, as well as timely intervention, to measurable health gains such as improved survival rate, reduced complications and disability, better quality of life and lower treatment costs. Primary prevention; modification of lifestyle factors and control of vascular risk factors, effective therapy in the prodromal stages, and secondary prevention; including diagnostic biomarkers and routine mental health screening, remain essential.

For instance, the treatment success rate in schizophrenia can be improved if

patients at risk are identified, psychotic symptoms are detected early and treatment is initiated in the prodromal phase. Depending on the stage of the disorder, antipsychotic medication, psychosocial interventions or both, are needed.<sup>10</sup> In multiple sclerosis, the key paradigm is early diagnosis and use of disease-modifying treatment. Such treatment at the early stage of multiple sclerosis can slow disease progression and subsequent disability. Primary and secondary prevention of modifiable risk factors can avert long-term disability due to multiple sclerosis and reduce its economic consequences.<sup>11,12</sup> However, many mental and neurological disorders still lack a cure and more studies are needed to understand the causes and reasons for progression of each disease. Research is also needed to develop new treatments that modify disease progression in addition to improving symptoms. ■

#### References

Available at: <http://www.who.int/bulletin/volumes/96/5/17-206599>

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*Bulletin of the World Health Organization, May 2018; Edition 96, 298–298A*  
<http://dx.doi.org/10.2471/BLT.17.206599>

## Overarching scientific publications

- EuroHealth Journal (January 2018)
- WHO Bulletin (May 2018)
- European Journal of Neurology (ongoing)

## Individual scientific publications

- European Psychiatry (Schizophrenia)
- European Journal of Epilepsy

## Value of Treatment

### Case studies on Rare Neurological Disorders (RNDs): Ataxia, Dystonia, Phenylketonuria (2018-2020)

In the continuity of the VoT research activities, new case studies will be conducted on new therapeutic areas. On March 26<sup>th</sup>, May 23<sup>rd</sup> and September 24<sup>th</sup> 2018, EBC launched a second round of case studies “VoT 2” related to Rare Neurological Disorders (RNDs) focusing upon Ataxia, Dystonia and Phenylketonuria. These meetings aimed to provide working groups (WGs) with a full description of the VoT research methodology framework and expected project deliverables.

The study will look at value, early intervention and will explore the potential benefits and consequences of coordinated care through the examination of health services, patient outcomes and patterns of multidisciplinary care. Case studies are conducted in collaboration with experts and with the support of Academic Partners (University College London and University of Zagreb Medical School), applying empirical evidence from different European countries.

### Case studies on Mental Disorders (MDs): Autism Spectrum Disorder, Eating Disorders, Major Depressive Disorder (2019-2021)

A second round of case studies on mental disorders will be launched on 18<sup>th</sup> January 2019, focusing on Eating Disorders (ED) and and Major Depressive Disorder (MDD).

EBC and the European Psychiatric Association (EPA) will work on these case studies on unexplored therapeutic areas, “Major Depressive Disorder (MDD)” and “Eating Disorders”, including the new topic of “continuity of care across age groups and services” (inpatient psychiatric care and outpatient mental health care).

In addition, a case study on Autism Spectrum Disorder (ASD) will be proposed and a kick-off meeting will take place in May 2019.





# ADVOCACY & OUTREACH





## Visibility

In 2018, EBC continued to significantly strengthen its role as a “one-stop-shop” for key stakeholders in health and health policy and recognition of our work by organizations such as the European Parliament, European Commission and European Union Member States increases.

EBC’s collaboration with the EU institutions, particularly the European Commission’s DG Research & Innovation, strengthened significantly in 2018 due to the increase of collaboration in EU H2020 projects, notably through the successful application of the European Brain Research Area (EBRA).

Furthermore, EBC maintained its influence at the level of the European Parliament through continued awareness raising events held under the auspices of various Members of Parliament (MEPs) on topics such as Alzheimer’s Disease and Mental Health in Elite Sport.

**For a full list of meetings, please consult Annex 1.**



## #ILoveMy Brain

EBC's **I Love My Brain** campaign was launched in 2017 as a communication tool aimed to promote and connect all the work being done to support brain health and to prevent and treat brain disorders in Europe, and continues to be used for all main forms of communication for EBC.

With the shared logo, the public and the media can more easily recognize the vast scale of the work being done on brain disorders, and their enormous impact on society. We want to continuously raise the awareness of EU policy makers and the general public to channel more time, resources and focus towards research on the brain and for patients living with brain disorders.

EBC welcomes and encourages all working in brain health to headline their work – fundraisers, policy events, publicity campaigns, research projects and health promotion programmes (in government, hospitals, universities, schools and community centres) – with the logo.



# Mental Health in Elite Sport

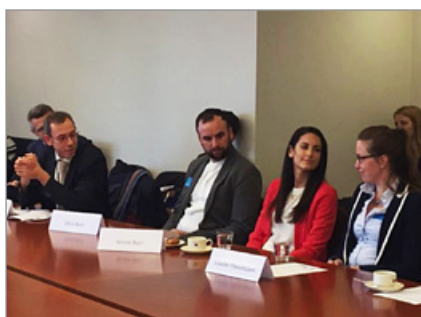
EBC marked this year's World Mental Health Day (10<sup>th</sup> October) with an event on Mental Health in Elite Sport at the European Parliament. Hosted by the EP Sport Intergroup with group member MEP Bogdan Wenta and co-planned with Vrije Universiteit Brussels, EBC was happy to work with a number of other partners to build a strong agenda demonstrating the vital role mental health has in professional athleticism.

Thanks to support from EUAthletes, FIFPro, TeamNL, EFPA and FEPSAC, the meeting had an excellent agenda of presentations by experts and a roundtable of athletes.

The morning started with a welcome from Mr Wenta, who spoke about the work of the intergroup, his experience as both a professional handball player and coach, as well as the important role good mental health plays in competitive sports.

Prof. Paul Wylleman from VUB gave an introduction to the topic, citing the Declaration for Athletes' Rights and Responsibilities calling for the protection of mental and physical health. A roundtable discussion, moderated by EBC Executive Director, Frédéric Destrebecq, featured three professional athletes: Chris Kerr (Gaelic Footballer, Antrim Gaa & St Galls GAC), Jessie Barr (Olympian; University of Limerick) and Lisette Teunissen (Paralympian Swimmer). The discussion revolved around their own personal experiences with mental health in their careers, the support that is available (or lack there of, in some cases) in the professional world, and the stigma that continues to discourage fellow athletes from seeking help.

Other speakers included Maurits Hendriks, Games and Performance Director of TeamNL, who spoke about "The organization of mental health support in Olympic and Paralympic sports", highlighting the holistic support TeamNL provides its athletes 365 days a year as well as Prof. Peter Falkai of Ludwig-Maximilians University Munich and the European Psychiatric Association, who gave a presentation on "Using resilience to build mental health in elite athletes and coaches", explaining the science behind resilience and what takes place in the brain as the athlete is building or feeding off their resilience.



## #Move4YrBrain

#Move4YrBrain is the European Brain Council's social media campaign used to encourage everyone to incorporate some form of exercise into their lives and keep a healthy lifestyle. A number of studies show that exercise not only makes you physically fitter, it also contributes to an improved mental and neurological condition by fostering the growth of new brain cells.

In order to encourage all to follow the #Move4YrBrain campaign and to raise awareness on the benefits of physical exercise for brain health, the EBC team tries to get involved in exercise activities, both personally and as a team. This year, 4 members of the EBC team took part in the annual Brussels 20km run together with colleagues from the Belgian Brain Council.



Furthermore, the EBC team dedicated a couple of days across the year to hold one-hour training sessions all together, including a session of laughs thanks to "Laughter Yoga" – the art of using movement, eye contact, jokes and playfulness in a group to turn compelled laughter into real and contagious laughter, which share the same physiological and psychological benefits.



A number of members of the EBC team also take part in weekly yoga classes held in the University Foundation, the location of the EBC office.



## COST Connect Event



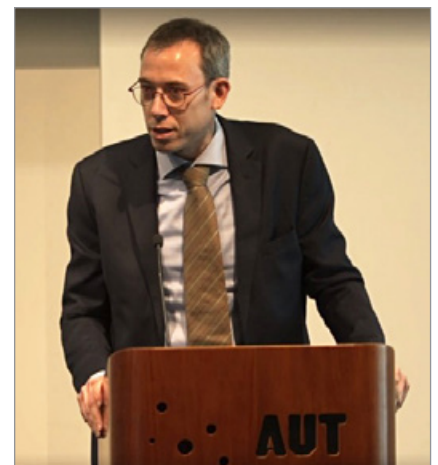
EBC took part in the COST Connect event this year, which provided a platform for fostering common understandings across various research initiatives in the field of brain research and aimed to identify and address knowledge gaps in brain research and coordinate research and innovation activities at a European level, by bringing together stakeholders with different perspectives to provide relevant perspectives and share good practices.

## Global Burden of Disease Brain Summit

On 27<sup>st</sup> November 2018, EBC was invited to speak at the Global Brain Summit, hosted by the Auckland University of Technology in Auckland, New Zealand, to celebrate the launch of a special edition of The Lancet Neurology devoted to a series of papers on the Global Burden of Disease (GBD) study.

The one-day summit brought together a large group of experts, best available data on the global burden of neurological disorders, and stakeholders committed to improving public health outcomes.

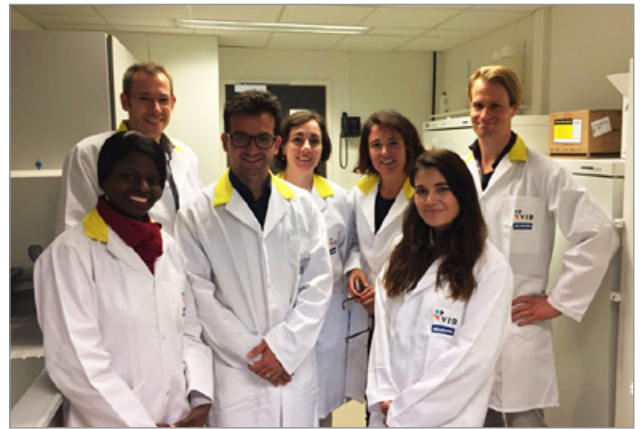
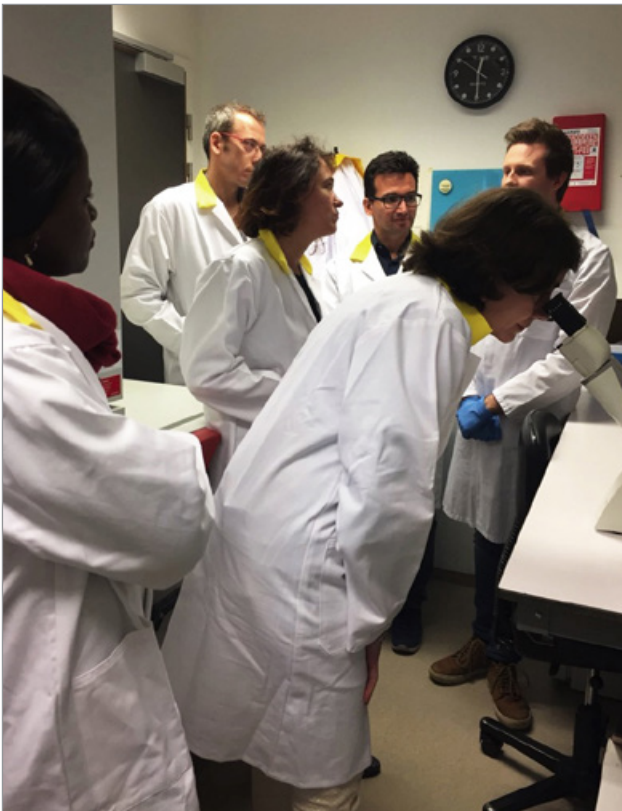
EBC Executive Director, Frédéric Destrebecq, travelled to Auckland to take part in the summit, presenting on “Effective coordination to maximise the impact of brain health and brain research”, highlighting the brand new EBRA (European Brain Research Area) project and the advocacy work of EBC.



## Team Visit to VIB

On 21<sup>st</sup> June, the EBC team visited the Verstreken Lab at the VIB-KU Leuven Centre for Brain Disease, to see brain research in action, meeting with the team for a lab tour, introduction & brainstorming session for potential collaboration.

The VIB-KU Leuven Centre for Brain & Disease Research brings together more than 300 scientists working on improving the understanding of brain health and disease, with the Verstreken Lab focused on Neuronal Communication, Synaptic function and Neurodegeneration.



## EBC's eHealth Agenda

Digital healthcare tools, including mobile applications and wearable devices, hold a tremendous potential to detect possible signs of various conditions, improve adherence to treatment and monitor cognitive abilities. What is more, these innovative solutions could provide patients with further insights into the progression and status of their condition. In view of the benefits of such technologies for patients and society, digital health has become an integral part of EBC's advocacy.

Since January 2018, EBC has been involved in the work of the Digital Therapeutics Partnership. This alliance, bringing together startups, research consortia and patient groups active in the domain of digital health, aims, amongst other issues, to build an enabling policy environment for digital healthcare. The most recent meeting, held on 19<sup>th</sup> November 2018, allowed all members to exchange perspectives on joint actions and set priorities for 2019.

EBC has also been involved in the "European AI Alliance", which constitutes a multi-stakeholder forum for engaging in discussion on all aspects of Artificial Intelligence (AI) development and its impact on society. The platform allows for interaction with the High-Level Expert Group on AI that was launched by the European Commission. This group, bringing together 52 experts that represent academia, civil society and industry, will develop AI Ethics Guidelines and advise the European Commission on AI-related challenges and opportunities. The first draft of the AI Ethics Guidelines was published on 18<sup>th</sup> December 2018.

On the occasion of the EBC Strategic Workshop held on 24<sup>th</sup>-25<sup>th</sup> September 2018, EBC's constituency discussed and considered strategic priorities in the domain of Digital-Health. During the meeting, delegates to the board of EBC reached consensus on a robust set of recommendations, including launching outreach activities that revolve around the value of digital tools, engaging with healthcare payors and payor representatives in order to demonstrate the benefits of digital solutions and developing case studies that demonstrate the efficacy of digital technologies.





## “New Approaches to Brain Disorders” Event, 21<sup>st</sup> November 2018

The Committee on the Environment, Public Health and Food Safety of the European Parliament (ENVI) is holding a workshop entitled, **“The Brain, A New Approach to Brain Diseases”**, on 21<sup>st</sup> November 2018 in the European Parliament.

EBC President, Prof. Monica Di Luca and EBC Treasurer, Joke Jaarsma, were invited to speak on major neurological disorders as well as framework conditions for tackling brain diseases in Europe, focused on the promotion of brain research at European level in order to improve the quality of life of people living with brain disorders in Europe.

The event brought together experts and key ENVI MEPs, including MEP Nessa Childers (S&D, IE) and Alojz Peterle (EPP, SI).





## “Uncorking the Brain” Networking Reception

2018 brought the introduction of a new version of EBC Board Dinners, now held in the form of a networking reception, with food, drinks and plenty of discussion.

The first of the series was held after the **“Enhanced engagement through public-private partnerships”** event on 21<sup>st</sup> November, with guest speakers Prof. Juan Lerma (FENS) and Dr. Joris De Wit (VIB Center for Brain & Disease Research) - pictured below. The aim of this informal reception setting is to allow for shorter more informal presentations that inspire audience conversation, continued brainstorming and fostering collaboration in a more relaxed atmosphere.



# COLLABORATION





# Academy of National Brain Councils

The 4<sup>th</sup> Academy Meeting of National Brain Councils (NBCs) was held from 17<sup>th</sup>-18<sup>th</sup> April 2018 at the Champalimaud Foundation located in Lisbon, Portugal. This event was the first annual meeting gathering NBCs organized outside Brussels and brought together delegates from 8 European countries.

The 2018 Academy Meeting was hosted by the Portuguese Brain Council and organized in conjunction with the EFNA workshop on “Value – Patient Preferences and Perspectives.”

Frédéric Destrebecq, EBC Executive Director, kicked off the meeting by updating the NBCs on EBC’s most recent initiatives as well as its outreach activities connected to the next EU Research and Innovation programme entitled “Horizon Europe”. Subsequently, the Norwegian Brain Council delivered a presentation on the Norwegian National Brain Health Strategy. This policy document, launched in December 2017, constitutes a robust tool for progressing brain research and enhancing brain health at national level. The NBCs that were represented in Lisbon reached consensus on working towards similar strategies in other European countries. What is more, EBC Vice-President Patrice Boyer presented EBC’s plans for continuing the Value of Treatment (VoT) project, underlining how NBCs could become involved in the dissemination of the results of the project.

The network of NBCs has actively supported EBC’s advocacy on Horizon Europe. In total, 11 NBCs and national partners responded to a call for feedback on the legislative proposals that are the basis for Horizon Europe, highlighting the need to allocate more funding to health research, that was launched during the summer of 2018. Furthermore, 8 NBCs immediately followed up by contacting their national decision-makers in order to stress the importance of making Horizon Europe a robust tool for supporting brain research. EBC’s “Counting Down to Zero” statement, calling on the EU institutions to increase the overall budget of Horizon Europe, was endorsed by 10 NBCs.

Further to the outcomes of the 4<sup>th</sup> Academy Meeting, EBC has worked on strengthening and expanding the network of NBCs. As such, EBC started hosting teleconferences that enable NBCs to connect and exchange views on joint initiatives and policy developments at national level. EBC will organize a Regional Meeting of NBCs, in cooperation with the Serbian Brain Council, on 10<sup>th</sup> July 2019.



# Alzheimer's Disease Policy White Paper

November 2018 saw the launch of a new policy white paper on Alzheimer's Disease: "Driving policy to optimise care for people with Alzheimer's Disease in Europe today and tomorrow".

Launched in the European Parliament on 21<sup>st</sup> November: during the European Federation for Neurological Associations (EFNA)'s Brain, Mind and Pain MEP Interest Group Meeting, the paper outlines clear priorities for change and proposes ideas for specific policy actions, which, if implemented, would significantly improve the care for people living with AD and the experience of their families and carers across Europe by supporting more patient-focused and sustainable care. The paper was developed in collaboration with a number of stakeholders, including EBC, EFNA and MSD.

Frédéric Destrebecq, EBC Executive Director, is quoted: "The European Brain Council (EBC) endorses this white paper on Alzheimer's Disease and its key areas for actions and policy recommendations. Alzheimer's is one of the largest public health crises facing Europe; yet in the face of this growing challenge, and despite AD and dementia being high on the health policy agenda at EU level and across Member States, there are still concerns that the current level of action is not sufficient. EBC thus emphasizes the fact that it is now time to challenge the status quo and refresh the European policy debate on Alzheimer's, come together to recognize the consequences of the burdens of AD in society and encourage multi-stakeholder-driven policy".





# Major Depressive Disorder (MDD) Policy White Paper

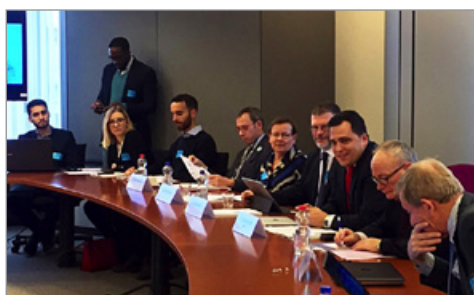
On 5<sup>th</sup> December 2018, the European Parliament Interest Group on Mental Health, Well-being and Brain Disorders - with co-hosting MEPs Tomas Zdechovsky (EPP, CZ) and Nessa Childers (S&D, IE) - EBC, GAMIAN-Europe, the European Psychiatric Association (EPA), EUFAMI, the Expert Platform on Depression, Eurocarers, the European College of Neuropsychopharmacology (ECNP), the UEMS – Sector of Psychiatry and the International Federation for Psychotherapy launched a joint policy paper on major depression, entitled 'A sustainable approach to depression: moving from words to actions', at the European Parliament in Brussels.

Today, over 35 million people are estimated to be living with depression in Europe. Its cost is 30% higher than that of stroke. Yet as a society, we lack understanding of depression and empathy for those affected. Policies focused on depression exist, but implementation is variable and suffers from significant under-resourcing. This in turn contributes to significant gaps in diagnosis and care: only 25% of people diagnosed with depression receive appropriate and timely care.

These gaps need to be remedied – and require a comprehensive, sustainable policy response, looking at how to prevent and manage depression across all aspects of society.



The organisations joined forces to address this need; they agreed to produce a report aimed at providing policymakers with concrete ways to better address the full spectrum of depression and its impact on our societies. The report drew from the practical experiences of a variety of innovative projects addressing different aspects of depression across the EU. Key factors and lessons learnt were identified which can help policymakers develop and put in place concrete, relevant and sustainable policies and initiatives.



The event was held in the Parliament to present the key findings of the report, showcase examples of successful projects addressing depression, exchange views on how depression can be prioritized on the EU and national policy agendas and forge links between relevant stakeholders and explore ideas for future cooperation to ensure better management of depression.



## “Brexit” Healthcare

During 2018, both the UK and the EU made preparations for a no-deal Brexit, which constitutes an outcome that could have implications for patients and researchers across Europe. In light of these circumstances, EBC worked together with 17 other healthcare organizations, across disciplines and disease areas, on raising awareness about the need to prioritize patient safety and medical research throughout the Brexit negotiations.

In order to express their concern about the progress that was made regarding areas affecting patients and public health, this stakeholder group organized the event “Brexit: the European Parliament’s role in prioritizing patients, public health and health security across Europe” in the European Parliament on 27<sup>th</sup> September 2018. This meeting, bringing together patient, scientist and industry perspectives, allowed for an exchange of views on steps that could be taken by decision-makers to ensure that patient safety and public health are prioritized during the negotiations.

During December 2017, the group of stakeholders launched a joint statement that underlined the following priorities:

- Bring close cooperation between the EU and UK on the regulation of medicines and medical technologies, to ensure that UK and EU patients will continue to have access to life-saving medicines and medical technologies.
- Establish a common framework for collaboration in research and information sharing between the EU27 and the UK.
- Ensure that there are continued reciprocal healthcare arrangements between the EU and UK.
- Develop strong coordination between the EU and UK on public health, including in pandemic preparation and disease prevention programmes.
- Ensure EU and UK health professionals continue to benefit from mutually beneficial training and education opportunities, with automatic recognition of qualifications.

# Multiple Sclerosis (MS) Policy Report and National Brain Plans with a focus on MS

## EBC & Health Policy Platform 2018-2019 Joint Project



Neurological disorders are among the world's leading causes of poor health and disability. Europe, in particular, has a high burden and frequency of brain disorders including multiple sclerosis (MS). MS is a complex and progressive disease of the central nervous system that places unique challenges upon European health and social care systems. Affecting more than 700,000 people in Europe, MS is the leading cause of disability in young and middle-aged people. Although many effective interventions exist, there are many gaps in both health and social care for people with MS across Europe.

To tackle some of these challenges, EBC and The Health Policy Partnership are building on the findings of the Value of Treatment report and developing a consensus around practical and sustainable policy responses to MS at the European level and in Denmark, Italy, Romania and Spain. By taking a pan-European view of healthcare and social services, identifying best practice and national priorities, we aim to create greater visibility for the unmet needs experienced by people with MS, with a particular focus on:

- 1) diagnosis and personalized treatment and care
- 2) multidisciplinary approach to care
- 3) participation in daily life.

With this, we will build a framework for policy change that is relevant to the very different national contexts across Europe, both now and in the future. This work, which started in April 2018, will culminate in the launch of a policy report and national brain-plan templates at the European Parliament in Brussels on 6<sup>th</sup> November 2019.



# Scientific Congresses

## EPA

EBC was present again this year at the 27<sup>th</sup> European Congress of Psychiatry, held in Nice, France from 3<sup>rd</sup>-6<sup>th</sup> March 2018.

Every year, the European Psychiatric Association's Congress brings together expert clinical psychiatrists, researchers and leaders of stakeholder organizations in the field of mental health. The 2018 Congress motto was **Mental Health: Integrate, Innovate, Individualise**.

As every year, EBC was provided a stand in the Exhibition Hall to disseminate our work and inform attendees of the work EBC does around mental health and how we represent our members, including EPA, in Brussels.

A **Joint EBC-EPA symposium** was also held, highlighting the **Value of Effective Transition of Care** in psychiatry, with a focus on ADHD and Eating Disorders. The session was co-moderated by EBC President Prof. Monica Di Luca and EPA President Prof. Silvana Galderisi, with an expert panel of speakers, Prof. Celso Arango (ECNP President), Prof. Philip Asherson, Prof. Ulrike Schmidt and Prof. Nicola Specchio.



# Scientific Congresses

## EAN

The 4<sup>th</sup> Congress of the European Academy of Neurology took place from 16<sup>th</sup>-19<sup>th</sup> June in Lisbon, Portugal.

EBC was present in the exhibition hall to raise awareness of the work being done in Brussels with the recently released Brain Mission and brain research advocacy work, as well as to continue dissemination of the Value of Treatment project.

EBC Vice-President Prof. Wolfgang Oertel and EBC Treasurer Ms Joke Jaarsma gave presentations at the Scientific Theatre, which allowed for 15 minute overviews of a series of topics. Their talk was entitled **"Mind the Treatment Gap!"** and covered the unmet needs of Europe in regards to treatment of patients, early intervention as well as a deeper insight into the RLS working group of the Value of Treatment project. Furthermore, Prof. Maura Pugliatti gave a presentation on **"Improved patient journey in neurology"**, which covered the results of the Multiple Sclerosis working group also within the Value of Treatment project.

EBC also took part in a joint session with EAN and EFNA on the Value of Treatment for Brain Disorders in Europe, chaired by Prof. David B. Vodusek, Prof. Maura Pugliatti, and EBC Vice-President Prof. Wolfgang H. Oertel, with presentations on **Brain disorders in Europe: unmet needs, The value of early diagnosis and treatment. A patient journey, The Value of Treatment: using economic modelling to assess costs and outcomes associated with health-care interventions, The value of early treatment.**



# Scientific Congresses

## FENS

The bi-annual, 11<sup>th</sup> FENS Forum of Neuroscience took place in Berlin, Germany on 7<sup>th</sup>-11<sup>th</sup> July. EBC was pleased to have multiple sessions as part of the 5-day agenda, kicking it off with a poster session during the IBRO Global Advocacy Initiative Networking Reception as well as an introduction into the work of EBC by EBC President, Prof. Monica Di Luca.

EBC held a Special Interest Event on '**Structuring the future of brain research in Europe**', which explored how the 9th Framework Programme, "Horizon Europe" can accelerate brain research across Europe in view of the preparations for the forthcoming EU research scheme and how to bring attention to the current barriers that affect basic and translational research and facilitate an exchange of views on how the post-2020 Framework Programme can make a real difference for patients living with brain disorders.

EBC President Prof. Monica Di Luca started the session with an introduction into EBC's calls for a Brain Mission in the supposed "mission-oriented" framework programme, followed by EBC Executive Director Frédéric Destrebecq stepping in to deliver the presentation of DG Research & Innovation regarding their work in the preparation for Horizon Europe and what it will mean for the next round of science funding. Prof. Patrik Verstreken, Scientific Director & Group Leader, VIB Center for Brain & Disease Research, KU Leuven gave a scientist's perspective on FP9 and EU funding programmes as an ERC recipient. The session was rounded up by a presentation on funding and political influence from EBC Vice-President Prof. Wolfgang Oertel and led into a discussion with the audience.

Furthermore, EBC embarked on an exciting partnership with US-based **Tianqiao and Chrissy Chen Institute (TCCI)** to release a "sneak peek" into their upcoming neuroscience documentary, MINDS WIDE OPEN. The viewing was followed by a panel discussion led by Dr. Beth Stephens (Boston Children's Hospital) with Prof. Monica Di Luca (EBC President), Dr. Megan Carey (FENS Kavli Network Scholar) and Prof. Eero Castren (Incoming FENS Secretary General) tackling topics such as young researchers, funding opportunities and the need for continued support and encouragement of neuroscience.

EBC was also present in the Exhibition Hall, where we were able to distribute the Brain Mission, Consensus Statement and present our new poster with general introductions to our work.







1. EBC Special Interest Event on '**Structuring the future of brain research in Europe**'
- 2-3. EBC & Chen Institute 'MINDS WIDE OPEN' documentary preview reception
4. EBC Stand
5. Prof. Patrik Verstreken presents on the importance of basic research to understand and target neuronal disease during the EBC Special Session

# Scientific Congresses

## ECNP

The 31<sup>st</sup> Annual ECNP Congress took place on 6<sup>th</sup>-9<sup>th</sup> October in Barcelona, Spain. The congress attracts up to 6000 delegates, and is the largest European congress of applied and translational neuroscience. The annual ECNP Congress is Europe's premier scientific meeting for disease-oriented brain research, attracting neuroscientists, psychiatrists, neurologists and psychologists from around the world.



EBC was present with an exhibition stand to inform attendees of our work and to disseminate the EBC Brain Mission.



EBC STRIVES  
FOR A WORLD  
WHERE  
PREVENTION,  
EARLY  
DIAGNOSIS &  
TREATMENT OF  
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AND RESEARCH  
OF THE BRAIN  
IS PRIORITIZED  
BY SOCIETY.



# EBC MEMBERS & PARTNERS





## Full Members



The **European Federation of Neurological Associations** (EFNA) brings together European umbrella organizations neurological patient advocacy groups, to work with other associations in the field of neurology and advocate for better quality of life for people in Europe living with a neurological disorder.

[www.efna.net](http://www.efna.net) / @EUneurology



**GAMIAN-Europe** represents a coalition of patient organizations, placing the patient at the centre of all issues of the EU healthcare debate. The organization aims to bring together and support the development and policy influencing capacity of local, regional and national organisations active in the field of mental health.

[www.gamian.eu](http://www.gamian.eu) / @GamianE



The **Pan European Regional Committee** (PERC) of the **International Brain Research Organization** (IBRO) is a global organization resulting from the union of neuroscience organizations with the aim to promote and support neuroscience training and collaborative research around the world. The IBRO-PERC is a Pan European Regional Committee supporting the IBRO mission and helping to plan and implement IBRO activities in Europe. In the last few years, IBRO-PERC has established collaborations with European organizations to promote neuroscience in Europe at all levels, including the training of the next generation of European neuroscientists as well as stimulation of using scientific knowledge to develop and improve treatments of disease.

[www.ibro.org](http://www.ibro.org) / @ibroSecretariat



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](http://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](http://www.europsy.net) / @Euro\_Psychiatry



The **European College of Neuropharmacology** was established at the instigation of European scientists to encourage research and facilitate exchange in the convergent disciplines of neuropsychopharmacology. ECNP is committed to ensuring that advances in the understanding of brain function and human behaviour are translated into better treatments and enhanced public health.

[www.ecnp.eu](http://www.ecnp.eu) / @ECNPtweets



The **European Academy of Neurology** (EAN) is a non-profit organization that unites and supports neurologists across the whole of Europe. The European Academy of Neurology (EAN) is a Society of National Neurological Societies and at the same time a Society of individual members. The purpose of is to promote "Excellence in Neurology in Europe". Currently, 45 European national neurological societies as well as 800 individuals are registered members of the EAN. Thus, the EAN represents more than 20,000 European neurologists.

[www.ean.org](http://www.ean.org) / @EANeurology



The **European Association of Neurosurgical Societies** (EANS) is a fast-growing, independent association, both of European neurosurgical societies and of individual neurosurgeons all over the world.

## Associate Members



The **European Chapter** is one out of five chapters of the **International Federation of Clinical Neurophysiology**. It encompasses at present 35 European and African member societies. The Chapter is represented by an Executive Board and the delegates of each Member Society.



The **European Paediatric Neurology Society** (EPNS) is a society for physicians with a research or clinical interest in Paediatric Neurology. With more than 1.500 members, the EPNS is a thriving and growing society which continues to play an important role in and beyond Europe by promoting training, clinical care and scientific research in the field of Paediatric Neurology.



The **European Federation of Associations of Families of People with Mental Illness** (EUFAMI) has an ongoing commitment to improve care and welfare for people affected by mental illness. EUFAMI has a number of programmes supporting people affected by severe mental illness and the organisations representing them across Europe.

# National Brain Councils



Belgium\*



Bulgaria



Croatia



Czech Republic



Finland



France\*



Germany



Hungary



Ireland



Luxembourg



The Netherlands



Norway\*



Poland



Portugal



Serbia\*



Slovenia



Spain\*

\*Also Observer Member of EBC

## Industry Partners







EBC  
BRINGS  
TOGETHER  
A NETWORK  
OF KEY  
PLAYERS  
IN THE  
“BRAIN AREA”

# MEMBERS' HIGHLIGHTS



## EFNA Activities in 2018 – A Summary

In 2018 EFNA chose to focus on young neurology patients. EFNA conducted a survey to explore problems faced by this age group, as well as their feelings around levels of understanding of their disorder and their engagement in advocacy work or patient groups.

Between March 12<sup>th</sup> and May 15<sup>th</sup> 2018, 1368 responses to the survey were received from 39 countries. Almost 80% of the respondents were female, with the majority of the responses coming from the areas of Multiple Sclerosis, Myalgic Encephalomyelitis, chronic pain and migraine. The top concern cited by respondents was 'access to medication/treatment', followed closely by 'isolation' and 'stigma'. This isolation and stigma could be attributed to the lack of public understanding of brain disorders. You can read the complete survey report here: [www.efna.net/efnayoungpeoplesurvey/](http://www.efna.net/efnayoungpeoplesurvey/)

This work provided the theme for EFNA's stand at the EAN Congress, held in Lisbon in June. EFNA's General Assembly took place at this time, along with a number of associated events. A Huntingtons Disease Awareness Session was held in association with the European Huntingtons Association and the European Huntingtons Disease Network. Together with the EAN and the European Brain Council (EBC), EFNA also hosted a special session on Monday 18<sup>th</sup>, examining the **'Value of Treatment of Brain Disorders'** and highlighting the example of Restless Legs Syndrome (RLS).

**The 'Patient Advocacy in the Digital World' workshop took place in Brussels from Monday, November 19<sup>th</sup> – Wednesday, November 21<sup>st</sup>, as part of EFNA's Training Initiatives for Neurology Advocates [TINA] programme. This workshop was open to 18 – 35 year olds from around Europe who are affected by brain disorder. Participants in the workshop heard from other young advocates who are using digital technologies to share their stories and raise awareness. They also learned about how technologies are being used to improve patient quality of life, and about the EU's objectives in this area.**

Three other pan-European TINA events took place during 2018. A workshop on 'Value – Patient Preferences and Perspectives' was held in Lisbon in April. The 'Science for Advocates' **event took place in Berlin in July, alongside the FENS Forum, and a meeting on 'The Future of Healthcare in the EU: Towards more sustainable healthcare organisations'** took place in Bucharest in October. You can read more about our TINA programme here: [www.efna.net/tina/](http://www.efna.net/tina/)



In 2018 EFNA also co-hosted, alongside Pain Alliance Europe, three meetings of the Brain, Mind and Pain MEP Interest Group. February's meeting looked at How can the EU #MakeWorkWork for young people affected by brain, mind and pain conditions. In June the Group explored Optimising Patient Relevant Outcome Measures for sustainable healthcare systems and strong economies, while November saw a discussion held around the Future of Healthcare in Europe – What next for brain, mind & pain?

Visit [www.brainmindpain.eu](http://www.brainmindpain.eu) for more.



In November 2018, EFNA held its third Advocacy Awards, at the Fondation Universitaire in Brussels. These awards recognise the contribution of individuals or groups to the development and promotion of advocacy for people with neurological disorders in Europe. This year, to coincide with EFNA's focus on young people, the awards were given to young advocates, in the categories of: Young Health Professional/Researcher, Young Digital Advocate, Young Volunteer Advocate and Young Policy-Maker. You can read more about the event and our winners here:

[www.efna.net/efna-advocacy-awards-2018/](http://www.efna.net/efna-advocacy-awards-2018/)



## 2018: A banner year for European psychiatry

**As the need for clear direction, strong leadership and international cooperation grows in all fields of mental health and mental health care, the EPA continues to contribute to European psychiatry through wide-reaching education, outreach and policy initiatives.**

In 2018, the EPA focused on maintaining its place as an important organisation for psychiatric education by launching its first online course. Over 7.100 learners were able to follow the course and exchange on the topic of Cognitive Behavioural Therapy, and their enthusiasm has led the EPA to develop an additional online course to be launched in 2019, this time on motivational interviewing.

For the first time, the EPA also established a prize for women psychiatrists working to improve mental health care in Europe, and awarded the prize to Professor Anita Riecher-Rössler during the Opening Ceremony of the 26<sup>th</sup> European Congress of Psychiatry, held in Nice, France from 3<sup>rd</sup>-6<sup>th</sup> March 2018.

Later in the year, a leadership team from the EPA was invited to visit and review mental health services in Bulgaria and advise the Ministry of Health regarding expert recommendations for change needed. The aim of this visit was to provide recommendations to help achieve more consensus and to allow much needed reforms in mental health services to be delivered.

Other highlights from 2018 include:

- The addition of 1 National Psychiatric Association Member, the Estonian Psychiatric Association
- The addition of 1 EPA Section on Eating Disorders
- The addition of 2 new membership categories for Associate Members and Student Members
- Launch of the InterACT, the Council of NPAs quarterly newsletter



*EPA President, **Prof. Silvana Galderisi**, speaks at the Opening Ceremony of the 26<sup>th</sup> European Congress of Psychiatry in Nice, France on 3<sup>rd</sup> March 2018.*



*Filming for the 2018 EPA Online Course takes place at the EPA Administrative Office in Strasbourg, France.*



*3<sup>rd</sup> December 2018: Joint EPA-GAMIAN Europe event as part of the European Parliament Interest Group on Mental Health, Wellbeing and Brain disorders meeting entitled: 'New horizons for person-centred research and care.'*

In 2018, the policy work of the EPA focused around the topic of person-centred research and care in mental health, which led to relevant achievements and steps forward.

In particular, the EPA welcomed patient organization GAMIAN-Europe and family organization EUFAMI as official members of the Board. Furthermore, the EPA organized multiple policy events, such as the EPA Forum in Nice entitled "Person-centred mental health care: outcomes that matter to patients and their carers" (3 March 2018) and the joint EPA-GAMIAN Europe meeting at the European Parliament on "New horizons for person-centred research and care" (3 December), as part of the work of the European Parliament Interest Group on Mental Health, Wellbeing and Brain Disorders.

At the same time, the EPA contributed to key EBC advocacy and project activities around brain and mental health research, such as the Brain Mission paper and the H2020 project, European Brain Research Area (EBRA), which launched in November 2018.

The EPA looks forward to the continuation of achievements and collaboration with EBC in 2019!



## FENS celebrated its 20<sup>th</sup> Anniversary at the FENS Forum 2018 in Berlin

The FENS Forum of Neuroscience took place on 7<sup>th</sup>-11<sup>th</sup> July 2018 in Berlin, where FENS was founded twenty years before, at the first Forum of European Neuroscience in 1998. With a comprehensive scientific programme and more than 3,500 abstracts, the FENS Forum brought together over 7,300 European and international neuroscientists.

The Forum was also the occasion to meet colleagues from all over the world and attend special events addressing topics such as gender bias in neuroscience, animal research, alternative careers for neuroscientists, funding opportunities in Europe, the future of brain research and much more.

In Berlin, the European Brain Council partnered in organising a special event on **'Structuring the future of brain research in Europe'** with The Tianqiao and Chrissy Chen Institute (TCCI) on the occasion of the European launch of 'MINDS WIDE OPEN', an innovative documentary featuring leading, international experts and compelling patient stories.

Botond Roska delivered the closing plenary lecture (the ERA-NET NEURON Lecture), which was the occasion to announce that the FENS Forum 2020 will be taking place on 11<sup>th</sup>-15<sup>th</sup> July in Glasgow, UK.

The Programme Committee chaired by Professor Fritjof Helmchen will establish the Forum 2020 scientific programme on the basis of proposals from scientists from all over the world and all areas of neuroscience research. The call for symposium and technical workshop proposals will be open from 25 March - 20 May 2019.

*FENS President  
**Barry Everitt**  
(2016-2018)  
at the FENS  
Forum 2018 in  
Berlin*



*FENS Forum  
2018 venue  
(CityCube)  
in Berlin,  
Germany*



2018 saw another full programme of initiatives to advance the science of the brain, promote better treatment and enhance brain health.

## In science:

- The **31<sup>st</sup> ECNP Congress** was held on 6<sup>th</sup>-9<sup>th</sup> October in Barcelona, Spain, attracting 5,056 participants from 100 countries, spanning the spectrum of applied brain science and CNS treatment research from basic science to clinical care.
- **European Neuropsychopharmacology** lifted its impact factor to 4,468, ranking 27 out of the world's 146 journals in psychiatry.
- Three **Targeted Network Meetings** were held on 10<sup>th</sup> October in Barcelona, Spain, on anxiety disorders across the lifespan, nutrition for mental health across the lifespan, and biomarkers for the prediction of suicidal behaviour.
- The **ECNP Networks** obtained major grants for Bipolar Disorders, Child and Adolescent Neuropsychopharmacology, Down Syndrome and Other Genetic Developmental Disorders (DSG2D), and Experimental Medicine, with several more proposals in the pipeline. The first Thematic Working Group (TWG) launched, on 'Prevention of mental disorders and mental health promotion.'
- The **Neuroscience-based Nomenclature** (NbN) project released its second revised edition covering 133 medications and a new Child & Adolescent version. The NbN app hit 38,000 downloads worldwide.
- The **ECNP Neuropsychopharmacology Award** was conferred upon Marion Leboyer, France (clinical) for her contributions to identifying the genetic and environmental risk factors in major psychiatric disorders.
- The **ECNP Preclinical Network Data Prize** for published 'negative' scientific results was awarded to Laura Luyten and Tom Beckers, Belgium.

- **More than 20 scientific meetings held every year**

- Spanning all aspects of scientific, educational, and regulatory dialogue
- Bringing together researchers and clinicians from over 100 countries for fruitful scientific exchange

- **300 young scientists trained every year**

- Paid for by ECNP



## In education:

- The **ECNP Workshop for Junior Scientists in Europe** was held on 15<sup>th</sup>-18<sup>th</sup> March in Nice, France, with 95 participants from 23 countries and 11 speakers. Eight participants were funded to speak at the 31<sup>st</sup> ECNP Congress, with 12 poster presenters receiving a € 500 Travel Award to attend the ECNP Congress.
- The **ECNP Workshop on Clinical Research Methods** was held in 7<sup>th</sup>-9<sup>th</sup> November in Barcelona, Spain, with 38 participants from 28 countries and 10 faculty.
- 15 junior scientists participated in the **ECNP Internship Programme**, experiencing short-term research internship opportunities in institutes across Europe.
- The **BBSRC-ECNP Advanced Methods for Reproducible Science Workshop** was held on 3<sup>rd</sup>-8<sup>th</sup> April 2018 in Windsor, United Kingdom, with 30 participants, 10 of whom, from Europe, were funded by ECNP.
- The **ECNP School of Neuropsychopharmacology** was held on 24<sup>th</sup>-29<sup>th</sup> June in Oxford, United Kingdom, with 49 participants from 24 countries and 14 faculty.
- The **ECNP School of Child and Adolescent Neuropsychopharmacology** was held on 8<sup>th</sup>-13<sup>th</sup> April in Venice, Italy, with 47 participants from 26 countries and 16 faculty.
- Three **ECNP Seminars in Neuropsychopharmacology** were held on 23<sup>rd</sup>-25<sup>th</sup> March in Volgograd, Russia; 20<sup>th</sup>-22<sup>nd</sup> April in Odessa, Ukraine; and 16<sup>th</sup>-18<sup>th</sup> November in St Petersburg, Russia.

## In outreach:

- The **ECNP New Frontiers Meeting** was held on 18<sup>th</sup>-19<sup>th</sup> March in Nice, France, this year on the challenge of finding therapies for neurodevelopmental disorders; 73 participants from 21 countries and 12 speakers from Europe and North America.
- The **ECNP Brain Day** was held on 5<sup>th</sup> October in Barcelona, Spain, with seven speakers and 200 members of the general public attending.
- The three-year **ECNP Co-morbidity Study** continued under the direction of the London School of Economics (LSE) and Medical University of Vienna. It is due to be published in 2019.
- **Memberships and supporting grants** were continued for the Biomedical Alliance in Europe, European Brain Council (EBC), European Federation of Psychiatric Trainees (EFPT), Federation of European Neuroscience Societies (FENS), Expert Platform on Mental Health – Depression (EPD), and Global Alliance of Mental Illness Advocacy Networks (GAMIAN-Europe).





## Call to Action on Empowerment and Self-management of Care

In March, GAMIAN-Europe convened an expert workshop where a variety of leading EU-level and national mental health stakeholders with an interest in empowerment of patients and self-management of care were brought together to explore the current situation, identify barriers to empowerment and develop practical recommendations for action. Based on the outcome and content of the discussions, GAMIAN-Europe produced a draft Call to Action, which emphasizes the urgent need to stimulate the empowerment of those affected by mental ill-health and to recognize the vital role persons affected by mental ill-health can play in the management of their treatment and care, in partnership with health professionals and other care providers. The draft Call to Action was further discussed at a meeting on 16<sup>th</sup> May and formally launched on 26<sup>th</sup> September, endorsed by a wide variety of stakeholders. The Call, developed with the direct input from a variety of leading EU-level and national mental health stakeholders, addresses what can be undertaken concretely to overcome the pervasive disempowering attitudes and behaviours towards people affected by mental ill-health and contains targeted recommendations for a number of specific stakeholder groups. GAMIAN-Europe developed this Call as one of its priorities as the huge prevalence and impact of mental health conditions cannot be overlooked: 11% of the European population experience mental disorders every year. The proportion of national health budgets devoted to mental health ranges between 4% to 13% across the EU.



*MEP Tomáš Zdechovský and GAMIAN-Europe President Hilikka Kärkkäinen pictured with the Call to Action*

## 10<sup>th</sup> IBRO World Congress

The 10<sup>th</sup> IBRO World Congress will be held from 21<sup>st</sup>-25<sup>th</sup> September 2019, in Daegu, South Korea. The website ([www.ibro2019.org](http://www.ibro2019.org)) was launched in 2018, as well as the first travel grant application calls. The Scientific Programme Committee approved 40 symposia, featuring the best of international and regional neuroscience. In addition, the International Brain Initiative, the Global Neuroethics Summit, the International Brain Bee and global outreach and engagement events are also planned.



## International Brain Bee

The International Brain Bee (IBB) was formed by IBRO, FENS, Society for Neuroscience, American Psychological Association and the Dana Foundation in January 2018. It serves as an outreach program for high school students, inspiring them to pursue research and careers in the brain sciences. The Governing Board voted to hold the next world competition during the 2019 IBRO World Congress.

## Membership

IBRO membership continues to grow and reached 93 member societies in 2018. New members approved included the Egyptian Network for Neurodegenerative Disorders (ENND), Trisomy 21 Research Society (T21RS) in Spain, the Ghana Neuroscience Society and the Ageing and Dementia Research Group at Sultan Qaboos University in Oman. In addition, Torsten Wiesel (IBRO Past President, 1999-2005) was awarded an IBRO Honorary Membership at the 2018 IBRO Governing Council meeting in recognition of his long-term service to the organization.

## Science of Learning

IBRO's joint Science of Learning Fellows programme with the UNESCO International Bureau of Education was established in 2016 to support and translate key neuroscience research on learning and the brain to educators, policymakers and governments. In 2018, a second MoU was signed to extend this programme indefinitely. Our 2018 fellows included Pamela Mello Carpes from the Universidade Federal do Pampa in Brazil, Maria Castello Gomez from the Instituto de Investigaciones Biológicas Clemente Estable in Uruguay and Denes Szucs from the University of Cambridge in the UK.

## **IBRO-Kemali Foundation**

Guillermina López-Bendito, Senior Scientist at the Instituto de Neurociencias of the Universidad Miguel Hernández in Alicante, Spain, was awarded the 11<sup>th</sup> International IBRO-Kemali Prize at the 2018 FENS Forum in Berlin, Germany, and gave a special lecture on thalamocortical connectivity. The Kemali apartment in Naples, Italy, was renovated and can now be used for events such as the Young IBRO annual meeting. A pilot programme for scientists who want to do a 1-3 month sabbatical could also now be arranged at the apartment.

## **International Brain Initiative**

IBRO is working with the Kavli Foundation and several national brain project leaders to emphasize the importance of coordination at the global level through the International Brain Initiative. In 2018, an IBRO position statement was signed in February confirming IBRO support of the IBI in its commitment to fostering collaboration on brain research for the benefit of all and agreed to uphold the tenets outlined in the Initiative's Declaration of Intent. Since then, IBRO has been helping to develop the governing structure and working group scoping documents.

## **European Brain Council**

The IBRO Pan-European Regional Committee (PERC) represents basic neuroscience with FENS as members of the European Brain Council (EBC). Fabio Blandini from Italy continued to serve as IBRO-PERC's representative on the EBC Board. IBRO will participate as a third party in the EBC-led project called the 'European Brain Research Area' (EBRA) and support the project in communications, disseminating information, fulfilling project deliverables and aligning EBRA with global initiatives.

## **Global Brain Museum**

IBRO and FENS agreed to support the development of the Global Brain Museum, a new digital online resource that will show historical connections, impact and influence of brain research around the world and throughout history. A PhD student at EPFL in Lausanne, Switzerland, working with Sarah Kenderdine, Professor and Head of a new EPFL laboratory in experimental museology, has been commissioned to complete this project in the summer of 2019.

## **Neuroethics Task Force**

The IBRO Neuroethics Task Force was finalized in 2018. Co-chaired by Judy Illes (University of British Columbia, Canada) and Sharon Juliano (Uniformed Services University, USA), other members include Karen Rommelfanger (Emory University, USA), Laura Cabrera (Michigan State University, USA) and Sung-Jin Jeong (Korea Brain Research Institute, Korea). They are responsible for designing and implementing a neuroethics component for IBRO Schools in 2019. They hope to provide a global platform that is able to inform and be used by other neuroscience education and training programmes.



## Young IBRO

Young IBRO, a new IBRO committee supporting the needs of young and mid-career neuroscience researchers, was established in 2018. The first 10 members represent the five IBRO regions – Africa, Asia/Pacific, Pan-Europe, Latin America and US/Canada. Their first meeting focused on identifying problems, needs and concerns of young neuroscientists globally, and offering ways in which IBRO could help by proposing new initiatives. They will focus on 3 initiatives in 2019: Young IBRO Regions Connecting Awards to provide a mechanism that will foster international scientific collaboration between emerging research groups or between established and emerging groups; Young IBRO Hackathon & Open Neuroscience at the 2019 IBRO Canadian school; and Young IBRO-ALBA partnership which will build upon the ALBA network, a group of leading female and male scientists that aims to promote equality and counteract bias in Brain Sciences.



## Advanced Training

The Cajal Advanced Training Programme (co-funded by IBRO, FENS and the Gatsby Charitable Foundation) in Bordeaux (France) and Champalimaud (Portugal) and the African Centers for Advanced Training in Morocco and South Africa are now well established and running smoothly. Increasing its reach, IBRO agreed in 2018 to establish two new annual advanced training programmes with the Institute of Neuroscience in Shanghai, China, and the RIKEN Center for Brain Science in Wako, Japan. They will welcome the first participants in the summer of 2019.



## European Academy of Neurology (EAN)

The 4<sup>th</sup> Congress of the European Academy of Neurology (EAN) took place in Lisbon, Portugal from 16<sup>th</sup>-19<sup>th</sup> June 2018. Over 6000 neurologists took part in the congress. The congress' overarching theme was "Neurogenetics".



Every year, the Congress brings leading international experts in the different neurological fields together, addressing the new and exciting developments within Neurology; new diseases are being defined, new procedures are developed and introduced in clinical practice resulting in more accurate diagnosis, complex disease mechanisms are more and more unravelled, and current treatment options are extending.



Board elections took place during the congress in Lisbon and Prof. Franz Fazekas took over the presidency of the EAN.



# STAKEHOLDERS' HIGHLIGHTS



# EU Health Summit

The EU Health Summit, organized in view of the forthcoming elections of the European Parliament, was held on 29<sup>th</sup> November 2018 at the Crowne Plaza Hotel in Brussels, Belgium. EBC was amongst the group of 28 stakeholders that was involved in the organization of the event and endorsed the recommendations that were presented during the summit.

Pressing issues such as ageing populations, communicable diseases and chronic conditions currently present complex health-related challenges to healthcare systems and European society at large. The Summit organizers share a commitment to a positive future for European health and worked towards a robust set of recommendations for a shared vision for the future of health in Europe.

Amongst other issues, the recommendations call for establishing a Steering Board for Health, tasked with coordinating health programmes under Horizon Europe and for increasing the EU budget for health research.

The EU Health Summit enabled the stakeholder group to present the recommendations to an audience of key decision-makers, including:

- Cristian Silviu Busoi - Member of the European Parliament (EPP, Romania)
- Dan Octavian Alexandrescu - State Secretary, Romanian Ministry of Health
- Lieve Wierinck - Member of the European Parliament (ALDE, Belgium)
- Mark Pearson - Deputy Director of Employment, Labour and Social Affairs, OECD
- Martin Seychell - Deputy Director-General, DG SANTE
- Roberto Viola - Director General, DG CONNECT
- Tiemo Wölken - Member of the European Parliament (S&D, Germany)
- Wolfgang Bartscher - Deputy Director-General, DG RTD





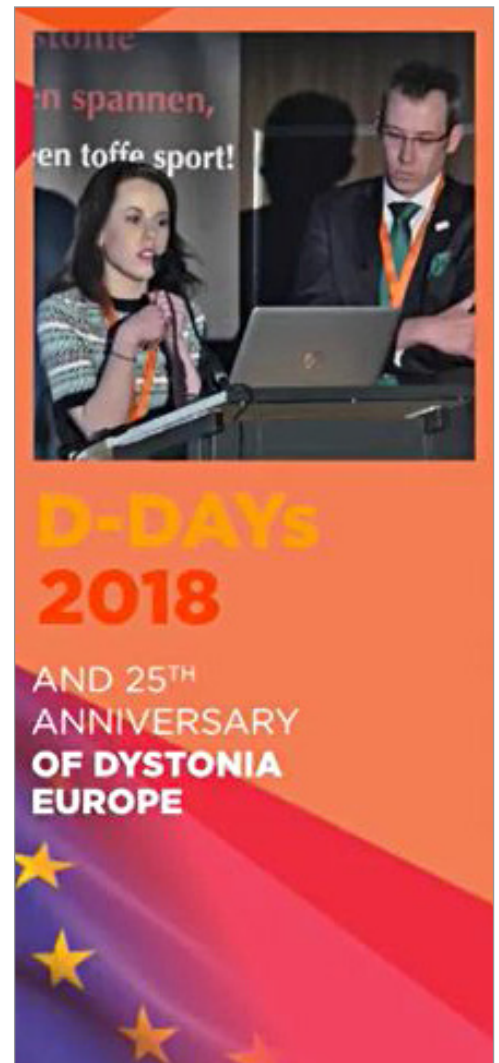
## 25<sup>th</sup> Anniversary Event - Dystonia Europe

On 12<sup>th</sup>-14<sup>th</sup> April 2018, the Dystonia Europe celebrated their 25<sup>th</sup> Anniversary in Brussels, Belgium with several events and activities. These included an event at the European Parliament and a 25<sup>th</sup> Anniversary Conference.

Dystonia Europe is a non-profit organization serving the needs of everybody with an interest in dystonia.

The Dystonia Europe vision is improved quality of life for people living with Dystonia in Europe, while supporting the search for a cure. They work to achieve their vision through raising awareness, sharing knowledge, connecting people and fostering training and education.

EBC Executive Director, Frédéric Destrebecq, joined EFNA Executive Director, Donna Walsh, on stage at the 25<sup>th</sup> Anniversary Conference to co-present on **Positive Partnerships for Brain & Neurology in Europe**, paying tribute to Dystonia Europe for being a driving force in the creation of both EBC and EFNA.



# Migraine & Headache International Patient Summit

The European Headache Alliance (EHA) - now called the European Migraine and Headache Alliance (EMHA) - held the 1<sup>st</sup> **Migraine and Headache International Patient Advocacy Summit** (MHIPAS) on 10<sup>th</sup>-13<sup>th</sup> May 2018 in Amsterdam, Netherlands.

The aim of the summit was to promote dialogue and exchange experience between all stakeholders involved in patient advocacy, extending also to non-European organizations (Canada, Mexico, USA, Australia, etc.) to bring a fresh perspective and best practice from across the globe. The meeting was a great opportunity to share hopes and concerns, so as to find the best way of strengthening collaboration in order to achieve common goals.

EBC's Executive Director, Frédéric Destrebecq and Research Project Manager, Giovanni Esposito, took part in the summit in Amsterdam, presenting the work EBC has done specifically on Headache within the Value of Treatment project.



# MEDIA REPORT





## HEALTH & SOCIAL CARE

### Implementing digital technology for brain health

Frédéric Destrebecq, Vinciane Quoidbach and Marijn Scholte from The European Brain Council (EBC) detail how the future of healthcare and improved brain health can be achieved through implementing digital health technology

The European Brain Council (EBC) is a Brussels-based organisation that gathers patient associations, major brain-related societies, as well as industries, with a mission to promote brain research in Europe to improve the quality of life of those living with brain disorders in Europe. As they join the eHealth conversation and digital technologies continue to develop at a rapid pace, plus the fact that the use of health data continues to widen, EBC firmly believes that the future of healthcare and improved brain health can only be achieved through implementing digital health technology that is properly designed. EBC, therefore, aims to join the forerunners in the digital movement. Brain health's digital future is clearly on its way.

Brain disorders are highly prevalent and disabling diseases and represent a tremendous burden on European society. A cost study conducted by the European Brain Council (EBC) in 2011 underlined that more than 1 in 3 Europeans, i.e. 179 million people, are likely to be affected by a disorder of the brain, the treatment of which is estimated to cost close to €800 billion annually<sup>1</sup>. Psychiatric and neurological disorders, ranging from schizophrenia, anxiety and Alzheimer's disease, to Parkinson's disease, epilepsy and multiple sclerosis, are the root of many chronic diseases<sup>2</sup> and represent 35% of the burden of all diseases in Europe<sup>3</sup>.

Despite the unprecedented scientific progress made in recent years, there is still no cure for a wide range of brain disorders, though effective treatments do enable faster recovery and better outcomes. Against this backdrop, EBC recently launched a Policy White Paper on the "Value of Treatment (VoT) for Brain Disorders in Europe", which provides a series of policy recommendations to address the unmet medical needs of people living with brain conditions. The VoT study highlighted the importance of using eHealth tools for solving issues

associated with treating brain disorders and that the proliferation of digital health tools, including mobile health apps and wearable sensors, has the potential to greatly improve the prevention and management of brain disorders<sup>4</sup>.

EBC aims to further explore the potential of eHealth for addressing challenges associated with brain disorders and has in this context contributed to the drafting of the Digital Health Society Declaration<sup>5</sup> and provided input to the public consultation on Health and Care in the Digital Single Market. It is crucial for organisations, such as EBC, that a Europe-wide regulatory framework gets implemented, allowing stakeholders to fully harness the advantages of digitalisation.

*"...It is important that decision-makers set clear future policy objectives in the domain of digital health and further explore opportunities for progressing the digital transformation of care delivery, to the benefit of millions of Europeans living with brain disorders."*

In this regard, EBC believes policymakers need to prioritise action in a certain number of areas such as health data sharing, mobile interventions or digital literacy. A recent report highlighted several potential benefits associated with the use of health data for research purposes, such as reduced duplication of research, the greater external validity of research and more opportunities to reveal patterns of causation (a result of linking datasets)<sup>6</sup>.

Additionally, a recent publication in the Journal of Medical Internet Research underlined the potential of applications and SMS text messaging for reducing symptoms of stress, depression and anxiety and highlighted the need for further investigation<sup>7</sup>. Finally,



healthcare professionals need to have the required ICT skills to successfully use digital solutions and therefore eHealth should become part of the curricula of healthcare providers.

These examples are few of many digital solutions and focus areas that can change the way in which healthcare is provided and highlight some of the potential advantages that digital health is likely to provide for the benefit of patients and society at large. In this regard, it is important that decision-makers set clear future policy objectives in the domain of digital health and further explore opportunities for progressing the digital transformation of care delivery, to the benefit of millions of Europeans living with brain disorders.

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## Implementing Digital Technology for Brain Health Open Access Government, February 2018



### European Psychiatry

Volume 53, September 2018, Pages 107-115



#### Original article

### Value of schizophrenia treatment I: The patient journey

Pavel Mohr<sup>a,b,\*</sup>, Silvana Galderisi<sup>c</sup>, Patrice Boyer<sup>d</sup>, Danuta Wasserman<sup>e</sup>, Paul Arteel<sup>f</sup>, Aagje Ieven<sup>g</sup>, Hilikka Karkkainen<sup>h</sup>, Eulalia Pereira<sup>g</sup>, Nick Guldemand<sup>h</sup>, Petr Winkler<sup>a,i</sup>, Wolfgang Gaebel<sup>j</sup>



Contents lists available at ScienceDirect

### European Psychiatry

journal homepage: <http://www.europsy-journal.com>



#### Original article

### Value of schizophrenia treatment II: Decision modelling for developing early detection and early intervention services in the Czech Republic

Petr Winkler<sup>a,b,\*</sup>, Hana Marie Broulíková<sup>a,c</sup>, Lucie Kondráťová<sup>a</sup>, Martin Knapp<sup>d</sup>, Paul Arteel<sup>e</sup>, Patrice Boyer<sup>f</sup>, Silvana Galderisi<sup>g</sup>, Hilikka Karkkainen<sup>h</sup>, Aagje Ieven<sup>g</sup>, Pavel Mohr<sup>a,i</sup>, Danuta Wasserman<sup>j</sup>, A-La Park<sup>d</sup>, Michella Tinelli<sup>d</sup>, Wolfgang Gaebel<sup>k</sup>

The EBC Value of Treatment project's Schizophrenia working group's findings on both the Patient Journey and Economic Analysis were published in Elsevier in 2018.

BRAIN HEALTH



**Collective Responsibility**

Brain health must have a prominent place in the upcoming Horizon Europe research framework programme, argues **Jerzy Buzek**

**Jerzy Buzek** (EPP, PL) is chair of parliament's industry, research and energy committee

The brain is the human body's most complex organ. When something in the brain goes wrong, its complexity makes it very difficult to identify the nature of the problem and fix it. Unfortunately, disorders of the brain are highly prevalent and account for 10 per cent of the global disease burden. In comparison, cardiovascular disease accounts for five per cent of the global disease burden while cancer's share is 10 per cent. Brain disorders will affect an estimated 38 per cent of the European Union's population and will cost European health services more than all the other disease sectors put together. Many brain disorders are highly disabling and chronic, and are leading non-communicable (NCD) diseases.

The World Economic Forum and the Harvard School of Public Health predict that NCDs will result in a cumulative loss in global economic output of \$47 trillion, or five per cent of GDP, by 2030. Principally, this will arise through heart disease, stroke, alcohol misuse and depression in high and upper-middle income countries. Three out of four of these diseases are brain disorders.

It is my strong hope that promoting brain research and brain health becomes one of the large-scale European 'missions' currently being devised. I could not imagine a better and more fascinating mission than to truly understand the brain and consequently better understand who we are"

This creates an enormous burden on those affected, their caregivers, their social environment, on health care systems and on society in general. Brain ill-health leads to enormous human suffering and restrains the independence of those living with a brain disease, not least as a result of disability and the need for care.

Without significant decisions and investments, the burden of NCDs - and in particular brain disorders - will become unbearable. It is likely to lead to a further increase in suffering of those affected, as well as threatening the sustainability of health care systems.

It is only through cross-border efforts and other bold decisions that we can properly address these challenges mortality linked to NCDs through better prevention and treatment as well as promoting mental health and wellbeing. This could prevent millions of premature deaths, avoid untold suffering and improved financial stability at the level of individuals, their households and families or their country as a whole.

The timing for addressing these challenges could not be better, as Europe is now in the midst of shaping its next EU Framework Programme for Research and Innovation Horizon Europe. In light of this, it is clear that brain science must have a substantial place within it.

In particular, it is my strong hope that promoting brain research and brain health becomes one of the large-scale European 'missions' currently being devised. I could not imagine a better and more fascinating mission than to truly understand the brain and consequently better understand ourselves.

The era of empty rhetoric and inaction is over. We have a collective responsibility towards future generations for our ability to face and reverse the challenges posed by brain disorders and to improve the lives of all people at risk, affected by or living with brain disorders. ✱

The Thought Leader is sponsored by EBC

TACKLING THE GROWING BRAIN DISORDERS HEALTH THREAT IS THE 21ST CENTURY'S SPACE RACE, WRITES MONICA DI LUCA

THE PARLIAMENT MAGAZINE'S

## THOUGHT LEADER

Brain disorders represent a global threat to our individual wellbeing, economic productivity, and intellectual capital. Yet, owing to pervasive social stigma, and thus a lack of awareness and data demonstrating their full burden, the real adverse impact of brain disorders is, in most cases, hidden.

on a dramatically larger scale. This is why, as President of the European Brain Council, I am calling for the brain to be included as one of the research missions in the upcoming Horizon Europe programme. In April, we released our proposal for a "Brain Mission: Understand - Fix - Enhance. The space race of the 21st century".

The target of our proposed brain mission is to decrease the burden of brain ill-health, neurological and mental alike through better understanding of the physiology of the healthy and diseased brain, relevant prevention strategies and, more generally, an increased awareness of the healthy brain and its diseases among EU citizens. Awareness among the general public is of particular importance. We

"Despite their significant contribution to the burden of disease and disability, brain disorders have largely been absent from the global health research agenda"

Some combined estimates indicate that the true global impact of brain diseases amounts to a staggering 11 per cent of all deaths, that's an estimated 17 million people every year. While brain disorders are currently affect one in three Europeans, other estimates suggest that this figure will increase to one in two by 2030. Health economists also estimate that brain disorders account for around 45 per cent of the annual health budget of Europe.

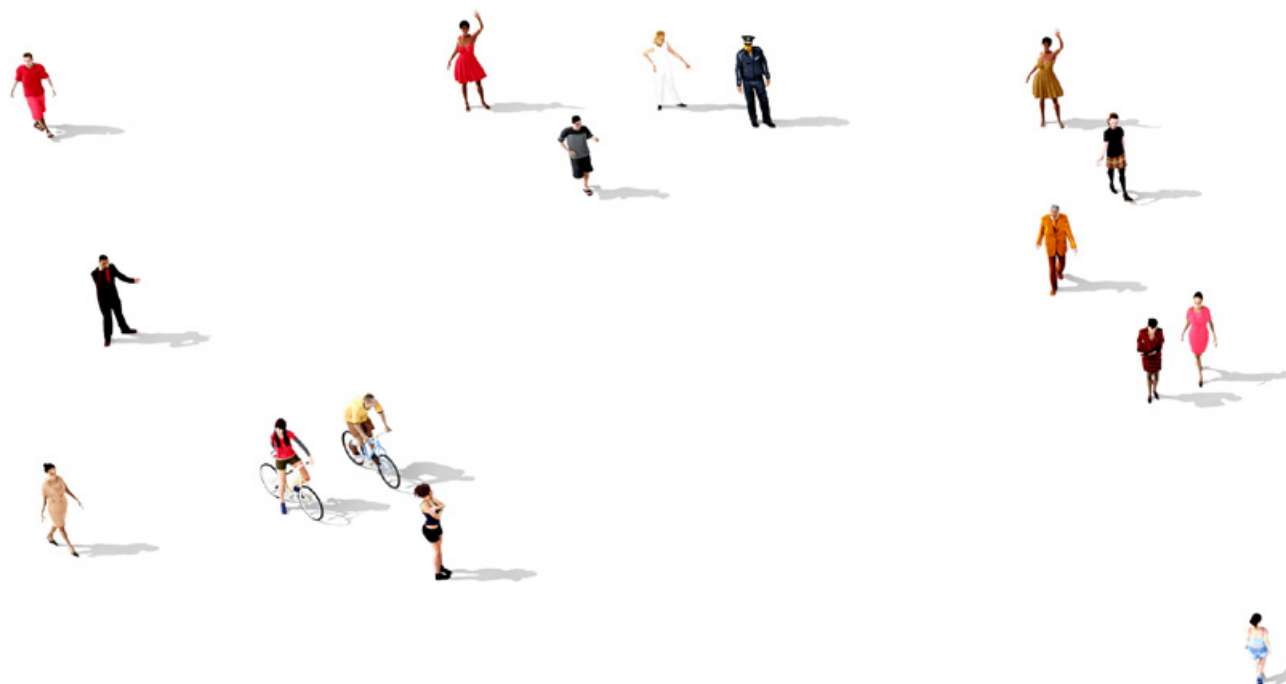
Despite their significant contribution to the burden of disease and disability, brain disorders have largely been absent from the global health research agenda; the reversal of this trend has only just begun. We are now at a crucial juncture in advancing this agenda. European Union countries must face up to the question of whether they want to commit the adequate attention and resources into preventing, curbing and healing brain disorders in the future. The existing political commitments need to be implemented

Monica Di Luca is President of the European Brain Council (EBC)

"As President of the European Brain Council, I am calling for the brain to be included as one of the research missions in the upcoming Horizon Europe programme"

want everyone to know how wonderful the human brain is, how to preserve, protect, develop and nurture it, and what the EU achievements and future plans are in this field. Last but not least, we would like Europe to take a global leadership in brain science. Without significantly expanding existing efforts, brain disorders will quickly turn into a ticking time bomb. We hope that our mission proposal will alert everyone to this threat and help galvanise actions to confront the rising tide of brain disorders.

**Collective Responsibility & Thought Leader** (MEP Jerzy Buzek & Prof. Monica Di Luca)  
Parliament Magazine, September 2018



## NEUROLOGICAL DISORDERS

No challenge is greater than that of understanding the brain. Professor Monica Di Luca, president of the European Brain Council, tells *Health Europa Quarterly* why more research is key to confronting the high burden of brain disorders in Europe.

## Brain disorders in Europe: the Space Race of the 21st Century

**N**on-profit organisation the European Brain Council (EBC) brings together patient associations, major brain-related societies and industry to promote neuroscience with the aim of improving the quality of life of the 170 million people living with brain disorders in Europe.

In April, EBC launched its Brain Mission, a dedicated effort to understand the brain, develop new treatments for existing diseases, and enhance patient outcomes. The Brain Mission was conceived in recognition of the fact that brain disorders have been largely absent from the health research agenda, despite their significant contribution to both healthcare costs and the global disease burden.

Speaking to *Health Europa Quarterly*, EBC president Professor Monica Di Luca discusses the mission and shares her hopes for brain research in the upcoming ninth European research and innovation framework programme, Horizon Europe.

### What are the objectives behind the Brain Mission launched earlier this year?

The Brain Mission was launched by EBC after a consultation with all our members. Its goal is to fully understand the brain and to cure its disorders, which we have identified as the main need and challenge of the 21st Century. The cost of brain disorders in Europe is enormous, reaching €800bn each year. In terms of people, one in three European citizens is going to experience a brain disorder during the course of their life, and epidemiological studies show that increased life expectancy will result in more and more brain disorders. In the future, treating them will become unavoidable.



In order to reduce the burden of brain disorders in Europe, we need to take a step back and begin with a full understanding of the brain itself. The brain is the most complex human organ, and for many years this has hampered our ability to fully understand both it and the pathogenic mechanisms of brain disorders. This is a crucial point: a full understanding of the brain is a prerequisite to curing and tackling the challenge.

To arrive at this understanding, we need more curiosity-driven research and we need to improve how we develop drugs for neurological disorders and mental illness. We also need to implement the technologies and tools that are now available for these purposes.

### How would you evaluate the brain-related initiatives under Horizon 2020, and what are your hopes for Horizon Europe?

In the past, brain research was clearly identified as a priority in the European Union, and this was

one of the main successes of the Seventh Framework Programme (FP7). Unfortunately this concept has been lost in Horizon 2020.

Having said that, it is important to recognise the effort the European Commission has made, as it hasn't discontinued brain research entirely. The Joint Programme for Neurodegenerative Disease Research (JPNDR) and ERA-NET NEURON have, in particular, been incredibly positive in the field of research. However, not all member states and institutions participate in these initiatives.

The portion of the Horizon 2020 budget that has been allocated to brain research is considerable, but it is completely fragmented. We would like to see a more harmonised way to fund brain research, and what we are really eager to see again in the next framework programme, Horizon Europe, is a return to 'brain research' being recognised as a priority for all Member States – that is, a dedicated sum being allocated to neuroscience. This is really important, and this is why we are insisting on the concept of a Brain



Mission, not just because we believe that brain disorders are going to be the biggest challenge of the next century but also because we are fully convinced that we need to harmonise all the calls and funding included in the framework programme if we are going to meet that challenge.

Something else that has been lost in Horizon 2020 is curiosity-driven research, which I've already mentioned. It is included in Pillar 1, Excellent Science, but the number of labs that can benefit from the impact of ERC-allocated funds is limited. In that sense, we have lost the momentum that we gained during FP7 with collaborative research projects dedicated to curiosity-driven research.

### The EU framework programmes have created a natural environment for collaborative research to flourish. How effectively has this been achieved in brain research, and what obstacles remain to co-operation?

Collaborative research is one of the added values of the framework programmes, and that was especially clear in the Sixth Framework Programme and FP7. EBC has played a key role in informing the European Commission of the needs and gaps in the research community. In the past, we have published what we call 'consensus documents' on brain research, which were an effort to map gaps in our knowledge of the brain and its disorders. In a 2011 document, we identified 46 priority research areas – including

preclinical and clinical – and they were fully reflected in FP7. Brain research was built a priority, and a lot of collaborative studies were funded.

That was extremely important, because it's vital that all the different disciplines – the scientists, the patient organisations, the industry – all learn how to work together. Now, it appears that this effort has been lost in Horizon 2020. One of our requests, therefore, is that collaborative research be reorganised into Horizon Europe.

### What is needed to translate the outcomes of research into new diagnostic tools and treatments for brain disorders in Europe, and what role does the European Brain Council play in this space?

In my opinion, the complexity of the brain has hampered – or, rather, delayed – the translation of research outcomes into tools and treatments. Having said that, very often, it has been said that we are not delivering, but if you look carefully at the management of patients with brain disorders in Europe nowadays, in comparison to 10-15 years ago, it has completely transformed.

Take, for example, the diagnosis of dementia, or Alzheimer's disease, in particular, which are two of the biggest challenges for the future. The diagnosis of Alzheimer's disease in its early stages in the patient using biomarkers and imaging tools is now possible, and this represents an incredible advancement in the field.

Multiple sclerosis (MS) is another example. Today we have drugs for MS that can be administered orally, and they have completely changed the lives of the patients who need them.

I am sometimes confused, therefore, when people say that we are not delivering results. Perhaps we need to communicate better with policymakers and even the public so that the results of brain research could be more effectively disseminated.

Of course, the complexity of brain disorders has delayed the main goal – cures for said diseases – and I would agree that complete translation is not yet there. We just need more time and secure funding.

EBC has recently launched a project called EBPA (European Brain Research Area) that aims to harmonise the different brain research and funding initiatives in Europe. We'd like to sit down with the JPNDR, the Human Brain Project and ERA-NET NEURON to discuss how we can achieve that and also reduce fragmentation in both funding and research, as well as to identify where the gaps in knowledge are and how we can facilitate translation. That is an enormous goal, but we hope we can achieve it.

**Professor Monica Di Luca**  
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## Brain Disorders in Europe: The Space Race of the 21<sup>st</sup> Century *Health Europa Quarterly*, November 2018





# FINANCIAL DATA

## Reports

Membership Fees	43%
EBC projects (non EU-funded)	41%
EBC projects (non EU-funded)	14%
EBC activities	2%



Team costs	34%
Meeting travel accommodation	13%
Services	39%
Advocacy and communication	11%
Other	3%



BY BRINGING  
TOGETHER  
SCIENCE &  
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UNDERSTANDING  
OF THE HEALTHY  
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LIVES OF THOSE  
LIVING WITH  
BRAIN DISORDERS

# EBC EXECUTIVE & BRUSSELS OFFICE





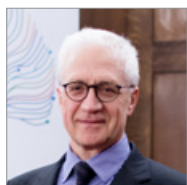
## EBC Executive



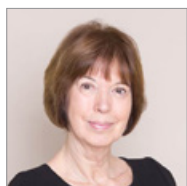
**Prof. Monica Di Luca**  
President



**Prof. Patrice Boyer**  
Vice-President



**Prof. Wolfgang Oertel**  
Vice-President

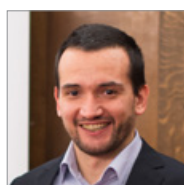


**Joke Jaarsma**  
Treasurer

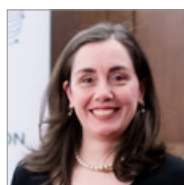
## EBC Brussels Office



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**Cécile Grebet**  
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Manager



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Office Manager



**Stephanie Kramer**  
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**Marijn Scholte**  
Policy Officer



**Vinciane Quoidbach**  
Public Health & Policy,  
Research Project Manager  
Value of Treatment Research  
Project



**Elke De Witte**  
Scientific Officer  
*\*Joins the EBC Team in 2019*

*The progress achieved in 2018 was made possible by the great efforts of EBC's Executive as well as the team at our Brussels Office.*

## Meetings Attended

- 24 January 2018 - STOA workshop 'EU mission-oriented research and innovation policy', Brussels
- 24 January 2018 - "Making Visible the Invisible On Headache Pain: Sharing Successful Experiences Across Europe», MEP Interest Group on European Patients' Rights & Cross-Border Healthcare Meeting, European Parliament, Brussels
- 24 January 2018 - "Darkness Into Light" Launch Event, European Parliament, Brussels
- 29 January 2018 - Identifying and transferring innovation in comparative Health Services and Systems Research, Brussels
- 30 January 2018 - Mental Health Europe event, "Coproducting employment initiatives for young persons with disabilities and mental health problems", European Parliament, Brussels
- 31 January 2018 - Health Commons, FP9 and Public-Needs Oriented R&D, Brussels
- 7 February 2018 - European Patients Forum "Patient Centricity Seminar", Brussels
- 13 February 2018 - "Meet & Greet Breakfast" with POLITICO Healthcare & Tech Writers, Brussels
- 20 February 2018 - 3<sup>rd</sup> Plenary Session of the European Health Parliament, Brussels
- 21 February 2018 - How can the EU: #makeworkwork for young people affected by brain, mind and pain conditions?, Brussels
- 27 February 2018 - "Cross-border healthcare and centres of excellence to enhance patients' rights: access, information and innovation", MEP Interest Group on European Patients' Rights & Cross-Border Healthcare Meeting, European Parliament, Brussels
- 3-6 March 2018 - 26<sup>th</sup> European Congress of Psychiatry, Nice, France
- 7 March 2018 - "Capital-to-Capital: Brussels to DC" Event, Brussels
- 8-9 March 2018 - EMA International Awareness Session - The EU medicines regulatory system and the European Medicines Agency, London
- 14 March 2018 - EBC, BBC and University of Strasbourg event, "Cerveau, coma, et (in)conscience", Strasbourg, France
- 15 March 2018 - EBC Brain Awareness Week Event: "Expanding brain research in Europe: Education, Behaviour and Brain Development", Strasbourg, France
- 21 March 2018 - Biomedical and health research: developing a vision for Europe, Brussels
- 21 March 2018 - Chrodis+ : Planning WP8 Meeting, Brussels
- 27 March 2018 - Bulgarian Presidency Reception, European Parliament, Brussels
- 24 April 2018 - 4<sup>th</sup> Plenary Session of the European Health Parliament, Brussels
- 25 April 2018 - Biomed Alliance Event: 'Maximize the value and the impact of health research in Europe', Brussels
- 14-15 May 2018 - MULTI-ACT Project Kick-off Meeting, Genova, Italy
- 16 May 2018 - European Parliament Interest Group on Mental Health, Well-being and Brain Disorders & GAMIAN-Europe Meeting on Suicide Prevention, European Parliament, Brussels
- 23 May 2018 - epiXchange 2018 Conference, Brussels

## Meetings Attended

- 24 May 2018 - "Shaping the Future of Epilepsy Research", European Commission, DG Research and Innovation, Brussels
- 31 May 2018 - The evolving thinking about diagnosis and treatment of Alzheimer's Disease, Brussels
- 4 June 2018 - MEP Interest Group on Access debate on the future of EU cooperation on Health Technology Assessment, Brussels
- 6 June 2018 - From health policy to practice: medical imaging as an example for improving patient outcomes through technology adoption, Brussels
- 6-7 June 2018 - Neuroconvention 2018, London, UK
- 16-19 June 2018 - European Congress of Neurology, Lisbon, Portugal
- 18 June 2018 - Health Innovation: Towards a Balanced Incentives Framework?, Brussels
- 20 June 2018 - Health Promotion and Disease Prevention: Finding the Right Ingredient, Brussels
- 27-28 June 2018 - Global Patient Advocacy Summit 2018, Brussels
- 4 July 2018 - Health Post-2019: Are EU in or are EU out?, Brussels
- 6-7 July 2018 - EFNA 'Science for Advocates' – Training Initiatives for Neurology Advocates (TINA) Workshop, Berlin, Germany
- 7-11 July 2018 - FENS Forum 2018, Berlin, Germany
- 8 July 2018 - IBRO Global Advocacy Initiative Networking Reception, Berlin, Germany
- 26 September 2018 - Aligning the priorities between the healthcare community and the European Parliament: Where we are now and the necessary next steps for a regulatory framework for HTA, Brussels
- 27 September 2018 - Big Data for Better Health: Hype or Hope?, Brussels
- 6-9 October 2018 - ECNP Congress 2018, Barcelona, Spain
- 11 October 2018 - Innovation in Non-Communicable Diseases prevention for young people, Brussels
- 18 October 2018 - International Consortium for Health Outcomes Measurement (ICHOM), Brussels
- 24 October 2018 - IMI Stakeholder Forum, Brussels
- 25 October 2018 - SIP Steering Committee Meeting, Brussels
- 7 November 2018 - Smart (dis)investment choices in healthcare, Brussels
- 12-13 November 2018 - 2<sup>nd</sup> MULTI-ACT Consortium Meeting
- 19-20 November 2018 - EFNA Patient Advocacy in a Digital World Workshop, Brussels
- 19-20 November 2018 - COST Connect – The future of European brain research, Brussels
- 20 November 2018 - EFNA Advocacy Awards and Gala Dinner, Brussels
- 27 November 2018 - Research and Innovation in our daily life, Brussels
- 29 November 2018 - EU Health Summit - A shared vision for health, Brussels
- 3 December 2018 - EPA-GAMIAN Europe European Parliament event, Brussel



## Annex of Speakers at EBC Board Meetings

### 7-8 February 2018 - EBC Board Meeting, Brussels:

- Dr. Ava Easton - EBC Ambassador & Chief Executive of the Encephalitis Society

### 15 March 2018 - Expanding brain research in Europe: Education, Behaviour and Brain Development, Strasbourg:

- MEP Anne Sander (France, EPP), European Parliament
- MEP Daciana Sârbu (Romania, S&D), European Parliament
- MEP Lieve Wierinck (Belgium, ALDE), European Parliament
- Prof. Albert Gjedde, Professor of Neurobiology and Pharmacology at the Faculty of Health Sciences and Department of Neuroscience at the University of Copenhagen
- Prof. Steven Laureys, Director, Coma Science Group at the University and University Hospital of Liège
- Prof. Gaia Novarino, Assistant Professor and head the Novarino Group at the Institute of Science and Technology
- Prof. Patrice Boyer, Vice-President, European Brain Council

### 17-18 April 2018 - 4<sup>th</sup> Academy Meeting of National Brain Councils, Lisbon:

- John Bowis, former MEP, former UK Health Minister and EBC Honorary Member
- Flora Giorgio, Head of Sector Health Technology Assessment, European Commission
- Nuno Silverio, Director of Market Access & Governmental Affairs, Merck
- Donna Walsh, Executive Director, European Federation of Neurological Associations
- Maria do Céu Machado, President, INFARMED - National Authority of Medicines and Health Products
- Alexandre Quintanilha, President of the Portuguese Parliamentary Commission for Education and Science

### 23-24 April 2018 - Expanding Brain Research in Europe - Shaping FP9 and Delivering Innovation to the Benefit of Patients, Brussels:

- Prof. Andrea Renda, Member of the Expert Group on the Economic and Societal Impact of Research and Innovation (ESIR)
- Prof. Monica di Luca, President, European Brain Council
- Jean-Eric Paquet, Director-General, Directorate-General for Research and Innovation, European Commission
- Joke Jaarsma, Treasurer, European Brain Council
- Hilikka Kärkkäinen, President, GAMIAN-Europe
- Jacobo Santamarta Barral, Young Person's Network at the European Multiple Sclerosis Platform
- Prof. Sebastian Brandner, Professor and Chair of Neuropathology Division of Neuropathology and Dept. of Neurodegenerative Disease, UCL Institute of Neurology
- Dr. Marisa Papaluca, Senior Scientific Advisor, European Medicines Agency (EMA)
- Dr. Christoph von der Goltz, Senior Director, Head of HEOR, RWE & Lu Institute, Lundbeck
- Menno Aarnout, Executive Director, Association Internationale de la Mutualité
- Matthias Wismar, Senior Health Policy Analyst, European Observatory on Health Systems and Policies
- Nathalie Moll, Director General, European Federation of Pharmaceutical Industries and Associations (EFPIA)
- Prof. Colm O'Morain, Past President, Alliance for Biomedical Research in Europe

## Annex of Speakers at EBC Board Meetings

- Margaret Walker, Executive Director, European Federation of Families of People with Mental Illness (EUFAMI)
- Alexander Schubert, Executive Director, European College of Neuropsychopharmacology (ECNP)
- Dr. Karim Berkouk, Acting Head of Unit, Non-communicable diseases and the challenge of healthy ageing, Directorate-General for Research and Innovation, European Commission
- Dr. Ari Ercole, CENTER-TBI and the International Initiative for Traumatic Brain Injury Research (InTBIR)
- Prof. Philippe Ryvlin, Co-Chair, Joint Task Force for Epilepsy Advocacy Europe, International League Against Epilepsy (ILAE)
- Dr. Helena Ledmyr, Head of Development & Communications, International Neuroinformatics Coordinating Facility (INCF)
- Prof. Philippe Amouyel, Chair, EU Joint Programme - Neurodegenerative Disease Research (JPND)
- Chris Ebell, Executive Director, Human Brain Project
- Dr. Hella Lichtenberg, Senior Scientific Officer, ERA-NET Neuron
- Prof. Wolfgang Oertel, Vice-President, European Brain Council

### 23-24 May 2018 - EBC General Assembly & Board Dinner, Brussels:

- Stéphane Hogan - Head of Sector for Neurosciences, DG Research & Innovation

### 24-25 September 2018 - EBC Strategic Workshop, Brussels:

#### VoT stakeholder meeting:

- Dr. Enrique Terol, Policy Officer, Directorate-General for Health and Food Safety
- Prof. Steve Morris, Health Economist, University College of London (UCL)
- Dr. Holm Graessner, Network Coordinator, European Reference Network on neurological diseases (ERN-RND)
- Simone Boselli, Public Affairs Director, EURORDIS

#### The structure and breakdown of Horizon Europe:

- Wolfgang Bartscher, Deputy Director-General, Directorate-General for Research and Innovation
- Nada Sirotić, Counsellor for Research, Innovation and Space, Permanent Representation of the Republic of Croatia to the EU
- Omar Cutajar, Research Attaché, Permanent Representation of Malta to the European Union
- Monica Dietl, Senior Advisor for the Healthy Measures Initiative, Science | Business

#### Moderators Strategic Workshop:

- Prof. Guy Goodwin, Past-President, European College of Neuropsychopharmacology (ECNP)
- Kim Baden-Kristensen, Co-founder & CEO, Brain+
- Margaret Walker, Executive Director, EUFAMI

### 25 September 2018 - The Socioeconomic Impact of Alzheimer's in Europe, Brussels:

- Ron Handels, University of Maastricht, The Value of Treatment project's Alzheimer's Working Group
- Prof. Philip Scheltens, Amsterdam UMC Alzheimer Centre, The Value of Treatment project's Alzheimer's Working Group
- Nis Nissen, Alzheimerforeningen Denmark
- Annette Dumas, ASDM Consulting, MOPEAD Project

- Elina Suzuki, OECD
- Margaret Walker, Executive Director, EUFAMI
- Stéphane Hogan, European Commission, DG RTD
- MEP Marian Harkin (ALDE, IE), European Parliament

### **10 October 2018 - Mental Health in Elite Sport, Brussels:**

- MEP Bogdan Wenta (EPP, PL), European Parliament
- Prof. Paul Wylleman, Vrije Universiteit Brussel
- Chris Kerr, Gaelic football, Ireland
- Jessie Barr, University of Limerick, Ireland
- Lisette Theunissen, Paralympian Swimmer, Netherlands
- Maurits Hendriks, Technical Director, TeamNL
- Prof. Peter Falkai, Ludwig-Maximilians Universität München, European Psychiatric Association (EPA)

### **21 November 2018 - Enhanced engagement through public-private partnerships: Sustaining therapeutic innovation to address patient needs, Brussels:**

- Dr. Pierre Meulien, Executive Director, Innovative Medicines Initiative (IMI)
- Prof. Patrice Boyer, Vice-President, European Brain Council (EBC)
- Prof. Wolfgang Oertel, Hertie-Senior- Research-Professor and Professor for Neurology, Philipps University Marburg, Germany and Vice-President, European Brain Council (EBC)
- Dr. Christopher Buckley, Senior Imaging Technology Leader, GE Life Sciences R&D
- Mr. Ulrik Ditlev Eriksen, Chief Science Officer & Co-founder, Brain+
- Danny Bar-Zohar, Global Head of Neuroscience Development, Novartis
- Sohini Chowdhury, Deputy CEO, Michael J. Fox Foundation
- Prof. Guendalina Graffigna, Associate Professor, Catholic University of the Sacred Heart of Milan
- Prof. Menno P. Witter, Director of the Norwegian Research School in Neuroscience, Norwegian University of Science and Technology (NTNU)
- Andrew Powrie-Smith, Communications Director, European Federation of Pharmaceutical Industries and Associations (EFPIA)
- Joke Jaarsma, Treasurer, European Brain Council
- Hugh Marston, Head of Translational Neuroscience, Eli Lilly UK
- Hilka Kärkkäinen, President, Global Alliance of Mental Illness Advocacy Networks (GAMIAN) - Europe
- Prof. Silvana Galderisi, President, European Psychiatric Association (EPA)
- Donna Walsh, Executive Director, European Federation of Neurological Associations (EFNA)
- Dr. Stefan Pype, Neuroscience Medical Affairs Lead, Janssen Benelux
- David Yeandle, MS in the 21<sup>st</sup> century Steering Committee
- Pieter Van Galen, MS in the 21<sup>st</sup> century Steering Committee
- Vanessa Pott, Director of Patient Advocacy & Strategic Partnerships, Merck
- Prof. Monica Di Luca, President, European Brain Council

### **21 November 2018 - Uncorking the Brain, Brussels:**

- Prof. Juan Lerma, Federation of European Neuroscience Societies (FENS)
- Dr. Joris de Wit, Vice Director, VIB-KU Leuven Center for Brain & Disease Research



# CREDITS

This report was compiled by  
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