



# **EBC ANNUAL REPORT**

**IMPROVING  
BRAIN KNOWLEDGE  
AND ADVOCACY**

**2017**

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# INTRODUCTION



Prof. David Nutt  
*President 2014-2017*



Frédéric Destrebecq  
*Executive Director*



Prof. Monica di Luca  
*President 2018-onwards*





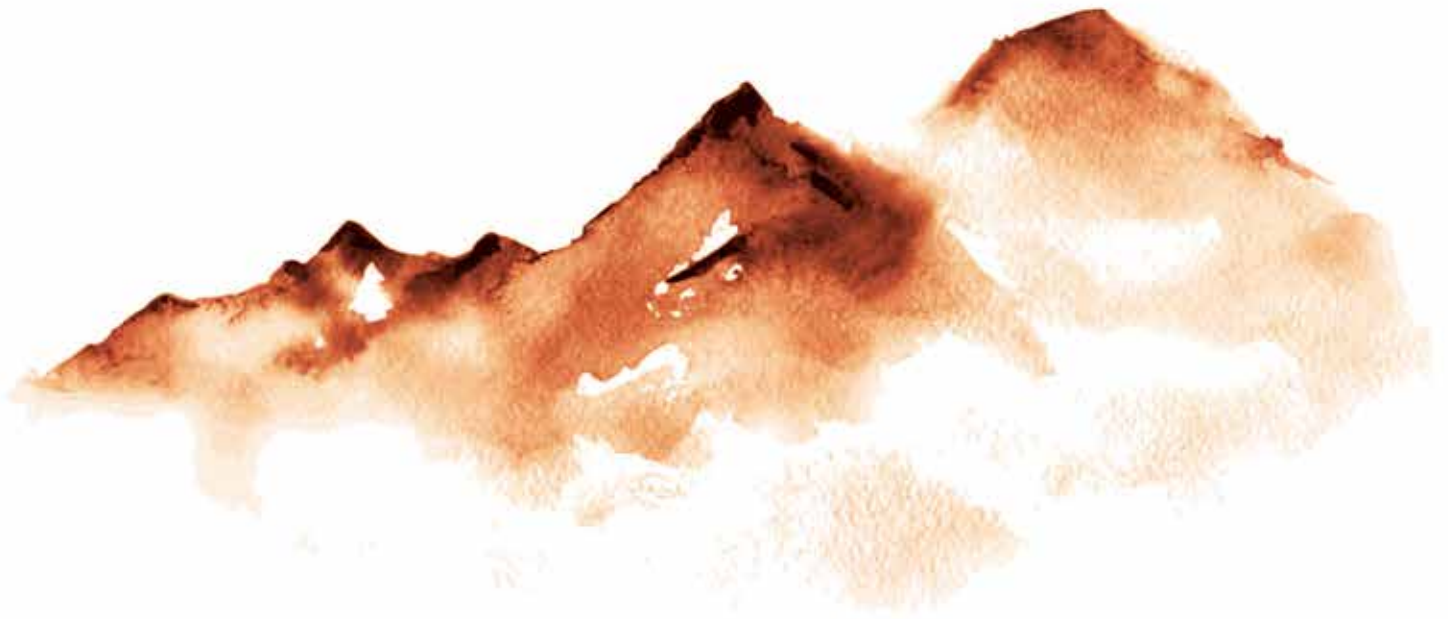
Dear Colleague,

The European Brain Council is pleased to present to you the Annual Report for the year 2017.

In its continuing efforts to support brain research in Europe and ensure that neurological and mental disorders are addressed at the EU -and international- level, EBC continues to work towards its mission and vision by delivering on key projects, as well as by supporting its members, to keep raising awareness on the need for sustained support to brain research and brain health in Europe. This has become particularly crucial with the start of discussions and negotiations on the future 9th framework programme.

2017 was a remarkable year for EBC, thanks to the development of an increasing number of activities and new initiatives. In particular, the publication of EBC's policy white paper on the "Value of Treatment for Brain Disorders in Europe" was key in this respect. So was the launch of our new brand "I love my brain".

All of EBC activities contributed to one objective: raising the awareness on the burden of brain disorders and on the need to continue to invest in brain research. This clearly will remain the backbone of EBC strategy in future and we look forward to many more successful achievements for EBC and its constituency in future!



# **EBC MISSION & VISION**

## EBC Mission

"By bringing together science & society we advance understanding of the healthy and diseased brain to improve the lives of those living with brain disorders".

### 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 in the society

### EBC realizes this through

- Policy and advocacy work as well as building awareness
- Driving prevention & treatment
- Stimulating innovation

## Research & Innovation Agenda

Brain disorders are highly complex conditions that impose a tremendous social and economic burden on European society at large. It is estimated that more than 1 in 3 Europeans, approximately 179 million people, are likely to be affected by a mental or neurological disorder. Additionally, data released by the Lancet indicated that the global burden of mental illness accounted for 13,0% of Disability-Adjusted Life Years (DALYs). Despite the fact that mental and neurological disorders are widespread, much about the functionality of the brain and the Central Nervous System (CNS) is still unknown, which hinders adequate diagnosis and treatment. Furthermore, the CNS drug development pipeline is beset by barriers such as high development costs, higher risk of clinical failure and long development timelines. This is a highly disturbing situation given that brain disorders, the treatment of which is estimated to cost close to 800 billion euro annually, are the cause of great human suffering across Europe.

In view of the burden represented by brain disorders and in the light of the increasing need for scientific knowledge on the functioning of the brain, the European Brain Council (EBC) has embarked on various initiatives and advocacy efforts in order to raise awareness about the need for allocating more funds to brain research and stimulate therapeutic innovation, to the benefit of those living with brain disorders.

## EU Research Funding

Preparations for the 9<sup>th</sup> EU Framework Programme (FP9), which is due to start in 2021, are currently ongoing and a proposal by the European Commission on the scope of this research scheme is expected for 2018. In order to cover various activities of the EU in the domain of research, the Commission will submit a proposal for the Multiannual Framework Programme, i.e. long-term EU budget, in the same year.

In view of the need of increased investments in brain research, EBC advocates for a robust and well-funded Framework Programme that aims to address the challenges that brain disorders impose on European society. In this regard, EBC has submitted written input in order to support the development of the “LAB – FAB – APP” report. This report, written by the High-Level Group on maximizing the impact of EU Research and Innovation Programmes led by Pascal Lamy, provides key recommendations for maximizing the impact of future EU research and innovation programmes. EBC is pleased that “understanding and enhancing the brain by 2030” is listed as a potential mission for FP9 (recommendation 5) and will continue to make a strong case for adopting a mission-orientated framework programme that aims to increase the understanding of the brain.

Additionally, EBC will submit a response to the consultation on EU funds in the area of investment, research & innovation, SMEs and single market that is expected to be launched by the European Commission in the first quarter of 2018.

## Therapeutic innovation

The increasing need of innovative treatments for people living with brain disorders as well as the current problems that affect the development of new CNS drugs for treating brain disorders were central to the discussion at the EBC Strategic Workshop held from 13-14 September 2017. In order to address these barriers and accelerate the discovery of new drugs, EBC adopted a tripartite strategy that aims to encourage the development of innovative treatments.

Firstly, the recommendation to work towards a proposed revision of the guidelines of the European Medicines Agency (EMA) on a neurological (Parkinson’s Disease) and mental (Schizophrenia) disorder was endorsed by the EBC Board. Measurement scales used in clinical trials for these conditions were often developed in the 1970s and 80s. Therefore, they could be considered outdated or no longer clinically fit for purpose, yet they remain part of the regulatory process. Given that a review is timely, EBC will develop a concept note for reviewing these guidelines. Additionally, EBC aims to establish dialogue with the EMA and national regulatory bodies in order to raise awareness of its plans for conducting a review. Based on how the proposal is received, EBC could work towards a full review of the guidelines and aim to have the recommendations that might follow from the assessment adopted by the EMA.



Incentivizing the development of innovative drugs and establishing a research and investment friendly environment, while guaranteeing access to existing drugs and treatments, is at the basis of the second pillar. In this regard, EBC provided a response to the European Commission's consultation on "supplementary protection certificates (SPCs) and patent research exemptions" which was written on the basis of input received by its members. Furthermore, the provided feedback will be central to an EBC statement on therapeutic innovation that will be drafted in 2018.

Finally, EBC actively supports the principles laid down in the Good Off-Label Use Practices (GOLUP) declaration. Off-label use, which is the practice of using a medicine outside its authorized indication, is often necessary in areas of unmet medical needs but poses challenges in terms of therapeutic innovation, patient safety and professional liability. There is currently no harmonized approach to off-label use across the EU. In this regard and to ensure that patient safety is not undermined by economic interests, EBC has endorsed the GOLUP-declaration which includes guidelines on when and how medicines could be prescribed off-label. EBC aims to organize workshops on member state level, similar to a roundtable organized in Brussels on 10 July 2017, in order to facilitate discussion on the practice of off-label use and raise awareness of the GOLUP declaration.

- Outreach letters to Labour Ministers on "Healthy Brains - Healthy Workforce - Healthy Society"
- Digital Health Society Declaration
- Co-signatory of the Basel Declaration (Animal Research)
- Annual Mental Health Stakeholder survey within framework of EU Compass for Action on Mental Health and Well-being
- Contribution to Consultation on Transformation of Health and Care in the Digital Single Market
- Publication review report of Directive 2010/63/EU (Animal Research)
- Endorsement of Call to Action Migration & Health
- Endorsement of Call to Action to enhance labour opportunities for people with chronic diseases
- Signatory of the Digital Health Society Declaration



# **EBC HIGHLIGHTS OF 2017**

## Election of the new executive & Farewell and Thanks to D. Nutt

On the 22<sup>nd</sup> of November 2017, the EBC Board held an election to determine the next Executive Board. We are pleased to announce the election of Prof. Monica Di Luca (FENS) as the new EBC President for the 2018/2019 term, with Profs Wolfgang Oertel (EAN) and Patrice Boyer (EPA) serving as Vice-Presidents and Ms Joke Jaarsma (EFNA) as Treasurer.

EBC would like to take the opportunity to bid farewell to our outgoing President, Prof. David Nutt, with whom it was an honour to work with over his two terms as EBC President.



## The Value of Treatment for Brain Disorders in Europe - Celebration Dinner

The full-day closing conference for the launch of the Value of Treatment white paper was preceded by a celebration dinner the evening prior, welcoming all members of the nine working groups and special guests.

The evening included speeches from two special guests, MEPs Adina Vălean (Chairwoman of the ENVI Committee) and Jerzy Buzek (Chairman of the ITRE Committee). Both assured support from the European Parliament for health, the brain and all living with brain disorders.



## Closing Conference & White Paper Launch

On 22 June 2017, the two-year EBC research project on the “Value of Treatment of Brain Disorders (VoT) in Europe” came to a close with the launch of a policy white paper including the data collected by 9 expert working groups.

Covering a range of mental and neurological disorders, the VoT study examined health gains and socio-economic impacts of best health interventions (pharmacological and psychosocial alike), and addressed the current early diagnosis and the treatment gap of the various brain disorders.

VoT wanted to explore bridging the early diagnosis and treatment gap, as despite the escalating costs of brain disorders, numerous needs of individuals at risk and patients are unmet, and around 8 out of 10 people living with a brain disorder remain non-treated or inadequately treated although effective treatments exist. Health services, generally, remain quite fragmented, and working groups collectively found that more patient-centred and seamless, interdisciplinary care is still needed. Furthermore, though there has been significant progress in brain research over the last 50 years, and basic and translational research are at a threshold for new findings with a major impact on treatment, continued investment into brain research remains as important and necessary as ever.

The conference, held under the auspices of the Maltese EU Presidency, focused on addressing the burden of diseases and issues in the current health care system, the health services delivery and care pathways design and proposing evidence-based and cost-effective solutions to achieve high value for patients.

Keynote speakers at the conference included Mr Martin Seychell, Deputy Director-General, Directorate General for Health and Food Safety, European Commission and Dr Line Matthiessen, Acting Director, Health Directorate, Directorate General for Research & Innovation, European Commission, as well as a panel of various experts from organisations like the European Commission, European Parliament, Organisation for Economic Co-operation and Development (OECD) and European Observatory on Health Systems and Policies discussed the policy recommendations provided in the White Paper, and views by patient and carer advocates such as The European Federation of Families of People with Mental Illness (EUFAMI) and AGE Platform Europe gave depth to the conclusions found by the two-year study.

With the completion of the first VoT project, EBC provided the necessary policy recommendations to address the treatment gap and its consequences for patients and citizens at large.



# Closing Conference & White Paper Launch



EBC Executive Director Frédéric Destrebecq welcomes the attendees



**Keynote** by Dr Line Matthiessen, Acting Director, Health Division, Directorate General for Research & Innovation, European Commission



The Value of Treatment Project Team and Working Groups



Conference attendees addressed by Dr. Line Matthiessen



Panel of Experts Discuss VoT (l-r): Dr Matthias Wismar (WHO European Centre for Health Policy ); Elina Suzuki (OECD); Stéphane Hogan (European Commission, DG RTD); Julie Ward MEP; Peter O'Donnell (Journalist)



**Keynote** by Martin Seychell, Deputy Director-General, Health and Food Safety Directorate General (DG SANTE), European Commission

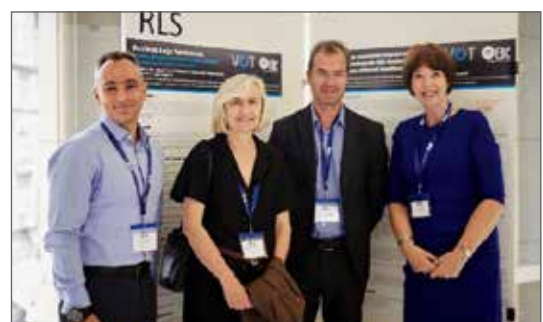


Official Value of Treatment poster

# Value of Treatment Dissemination: Working Groups Poster Exhibition

The launch event of the Value of Treatment on the 22<sup>nd</sup> of June was the first chance for the working groups to communicate their findings to the general public and relevant stakeholders.

Not only did all working groups have their work presented on stage by the working group leader, they also were able to present their work in poster form during the lunchtime poster session on the day. Each group produced two posters with the highlights of their case studies - one on the patient journey and the other on the economic analysis.



# Value of Treatment Dissemination: The Value of Early Intervention event at the European Parliament



On 12 July 2017, the meeting of the MEP Interest Group on Brain, Mind and Pain, and the Interest Group on Mental Health, Well-being and Brain Disorders took place in the European Parliament (Brussels) in partnership with EBC. The event was hosted by MEPs Jana Žitňanská, Marian Harkin, Michał Boni and Marek Plura.

The event was held under the title “The Value of Early Intervention in Brain, Mind and Pain Conditions”, and aimed to address the conclusions and recommendations from the EBC’s VoT research project and White Paper.

The first panel addressed the conclusions and recommendations of EBC’s Value of Treatment research project and White Paper, and explored the value of early intervention, using the case-studies of four disorders - presented from various stakeholder perspectives - and how the EU can support the solutions identified. The panel, led by Paul Arteel (GAMIAN-Europe), included presentations from the Stroke, Multiple Sclerosis, RLS and Schizophrenia working groups.



The second panel, chaired by Ann Little, President of the European Federation of Neurological Associations (EFNA), focused on the possible next steps in the Value of Treatment project – exploring the application of the developed methodology to other disease areas, e.g. rare diseases or chronic pain, as well as a future focus on interventions such as rehabilitation.

MEP Michał Boni began the discussion by discussing a move and need towards Integrated Care, and EBC presented the Value Proposition of a second VoT project.

The panel then continued into a discussion on potential case studies, addressing unmet needs, with presentations on rare diseases such as Ataxia and Myalgic Encephalomyelitis, as well as Chronic Pain.

Guest speaker Stephane Hogan, Head of Neuroscience, DG Research & Innovation gave his report on the work of the Commission and the continued support and dedication to brain research.



## Value of Treatment Dissemination: EU Presidency Estonia - Joint Meeting of the Chief Medical, Chief Nursing and Chief Dental Officers

On 5-6 July, a Joint Meeting of the Chief Medical, Chief Nursing and Chief Dental Officers was hosted in Tallinn by the Estonian EU Presidency. As one of the Estonian EU Presidency (July-Dec. 2017) health priorities, Stroke prevention and management was the highlight of the meeting.

Conclusions and policy recommendations from the EBC project on the Value of Treatment for Brain Disorders were presented with a special focus on stroke and "time matters", together with the WHO European Office, Stroke Alliance for Europe (SAFE), European Stroke Organization (ESO),

University of Tartu and the University of Helsinki. A Joint Experts Statement document (ESO, SAFE, University of Tartu, University of Helsinki and EBC) as conclusions of the meeting on "Stroke – better collaboration and equal access to evidence-based high-quality prevention, management and rehabilitation" was released.

## Value of Treatment Dissemination: 27<sup>th</sup> Alzheimer Europe Conference 2017

In partnership with MSD, EBC was invited to take part at the 27<sup>th</sup> Alzheimer Europe Conference in October 2017 to present the Alzheimer's Disease working group findings at the exhibition and during a special symposium on the 4<sup>th</sup> October, entitled *Early intervention in Alzheimer's disease: For a new understanding of AD across its spectrum*.

Moderated by EFNA Executive Director, Donna Walsh, the session explored the call for early intervention and putting knowledge and resources in the hands of patients and care givers, though facing a number of societal, ethical, technical and medical challenges. Our speakers explored the opportunities to monitor and

control the risk factors through eHealth interventions, assessed the potential socio-economic impact of treating AD before the onset of dementia and asked the question: would you want to know if you'll get Alzheimer's?





# Value of Treatment Dissemination: 11<sup>th</sup> European Headache Federation Congress 2017

In partnership with the European Headache Federation, members of which were part of the VoT Headache working group, EBC took part in the exhibition at the December congress in Rome.

EBC presented VOT white papers and headache working group results at an exhibition booth during the 3 days, presenting the work to congress attendees, which include healthcare professionals, headache specialists, academia and industry.

EHF dedicates its efforts to improving awareness of headache disorders and their impact within governments, health care providers and consumers across Europe. The congress included 3 intense days of exhibitions, poster presentations, lectures and social events.



## Value of Treatment Dissemination: The European Alliance for Personalised Medicine (EAPM) Congress 2017

On 28<sup>th</sup> November, EBC participated at the first annual Congress held by the European Alliance for Personalized Medicine (EAPM). The four-day event, entitled 'Personalizing Your Health: A Global Imperative' was held in Belfast under the auspices of the Estonian Presidency of the EU and in association with Queen's University Belfast and Visit Belfast.

EBC was invited to present the results and the policy recommendations of the VoT project at the special session on "The Value of Sustainable Health". The session brought together scientists, technologists, physicians, health economists as well as regulators and policy makers to discuss how to make healthcare systems more sustainable while ensuring improvement in the health of Europe's citizens.



"Based on existing plans of actions (Horizon 2020, EC Health Program 2014-2020)..., it is necessary to develop a EU-wide research and public health Brain plan" said Giovanni Esposito #EAPMBelfast2017

3:44 pm - 27 Nov 2017

## Value of Treatment Dissemination: VoT - Working Group's dissemination

Since the launch of the Value of Treatment findings, the working groups have been tasked with the post-launch dissemination and mass communication of their individual case studies. Whilst working on individual publications, the working groups took part in a number of congresses, meetings and exhibitions, where they were able to present and showcase their work.



MSParis2017 – Joint ECTRIMS-ACTRIMS Meeting, Presentation: *"Promoting healthier lifestyle contributes to averting multiple sclerosis long-term societal and healthcare costs: results from the VoT Project"*



Presentation by Ms Joke Jarsmaa of the RLS working group posters at an exhibition booth during the World Sleep Congress 2017, Prague, Czech Republic (7-11 October 2017)



Prof. Wolfgang Gaebel, Schizophrenia Working Group Leader, presents the case study during the "Value of Treatment: Schizophrenia" symposium at the 25<sup>th</sup> EPA Congress in Florence, Italy (1-4 April 2017)



Prof. Günther Deuschl, EAN President and Parkinson's Disease working group member, presents the Value of Treatment project at the Opening Ceremony of the 3<sup>rd</sup> EAN Congress in Amsterdam, Netherlands. All neurology working group posters were digitally displayed during the four day congress in June.





# Brain Awareness Week 2017

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 two outreach events covering the topic *"Brain research in Europe - a societal need?"*

The first event took place on 14<sup>th</sup> March in Brussels in the form of a lunch debate, and brought together an audience of civil servants, European and International Organization's officials, patient representatives, health professionals, clinicians, researchers, scientists and other stakeholders from the health and research community. Supported by Janssen and in partnership with members FENS, ECNP, and GAMIAN-Europe, the event was designed to start a conversation and work in alignment with the EU institutions relevant to health and research, and brought together speakers representing the European Commission, Neurology, Neuroscience and patients.





# Brain Awareness Week 2017

The second event was hosted by Ms Anne Sander MEP and Mr Momchil Nekov MEP on 16<sup>th</sup> March at the European Parliament in Strasbourg, France, during the plenary session. EBC, in collaboration with The Dana Foundation, The Belgian Brain Council, The European Psychiatric Association (EPA) and The Federation of European Neuroscience Societies (FENS), organized an outreach event at the European Parliament, Strasbourg on 16 March 2017. The title of the event "Expanding Brain Research in Europe: A societal Need?" was in parallel to the Lunch debate.

The goal of the event was to target MEPs and decision makers interested in the fields of health, research and innovation, as well as the general public, in order draw attention, with overarching perspective, to the need for the expansion of brain research in Europe and the latest developments.

The event at Strasbourg consisted of three presentations given by guest speakers: Prof. Monica DiLuca, Prof. Marion Leboyer, and Ms Ann Little.

The event was highly successful, with a good showing of policymakers, researchers and the general public who openly interacted with each other and the speakers during the hour of open discussion following the presentations.



EBC President Prof David Nutt was invited to present at the 2017 Tedx Brussels event, a full afternoon of live talks by world-class speakers on a diverse range of topics, held at BOZAR, Brussels.



The theme for this year's TEDx Brussels was "No Limits", and in keeping with this theme, Professor Nutt's talk titled "No Limits: To the Brain?" spoke of his work and research, addressing the potential for psychedelic drugs to expand consciousness and heal dysfunctions of the brain. With the treatment gap for brain disorders remaining the largest, despite effective treatments, Prof Nutt's TEDx Talk proposed, especially for the sake of those who could be helped, that it's time "to say there should be NO LIMITS to therapeutic research with these drugs".







A watercolor illustration of cherry blossoms in various shades of blue and white. The flowers are in different stages of bloom, with some showing detailed stamens. The leaves are dark blue and have a textured, painterly appearance. The background is white with some light blue washes and splatters, giving it a soft, artistic feel.

# **PROJECTS & INITIATIVES**



## EU-Funded Projects - AETIONOMY AND MARATONE

2017 saw the end of a 4-year long project MARATONE, an EU funded Marie Curie Sklodowska Initial Training Network initiative that addresses the need for high-level training and career pathways in mental health, to increase the employability of young scientists in the academic, public and private sectors, to meet the challenge of the 2009 EU Resolution on Mental Health.

The objective of the programme was to create a network of multidisciplinary and inter-sectorial training through research that will build career pathways for young scientists in mental health and meet the challenge of a comprehensive and integrated mental health strategy for Europe.

14 early stage researchers (ERSs), which had been recruited among 13 beneficiaries, carried out their PhDs and over 20 publications and manuscripts by ESRs were published in peer reviewed journals during the project duration. The results of this work contributed to providing a basis of larger research and influence future mental health policies across Europe.

MARATONE's main research topics were:

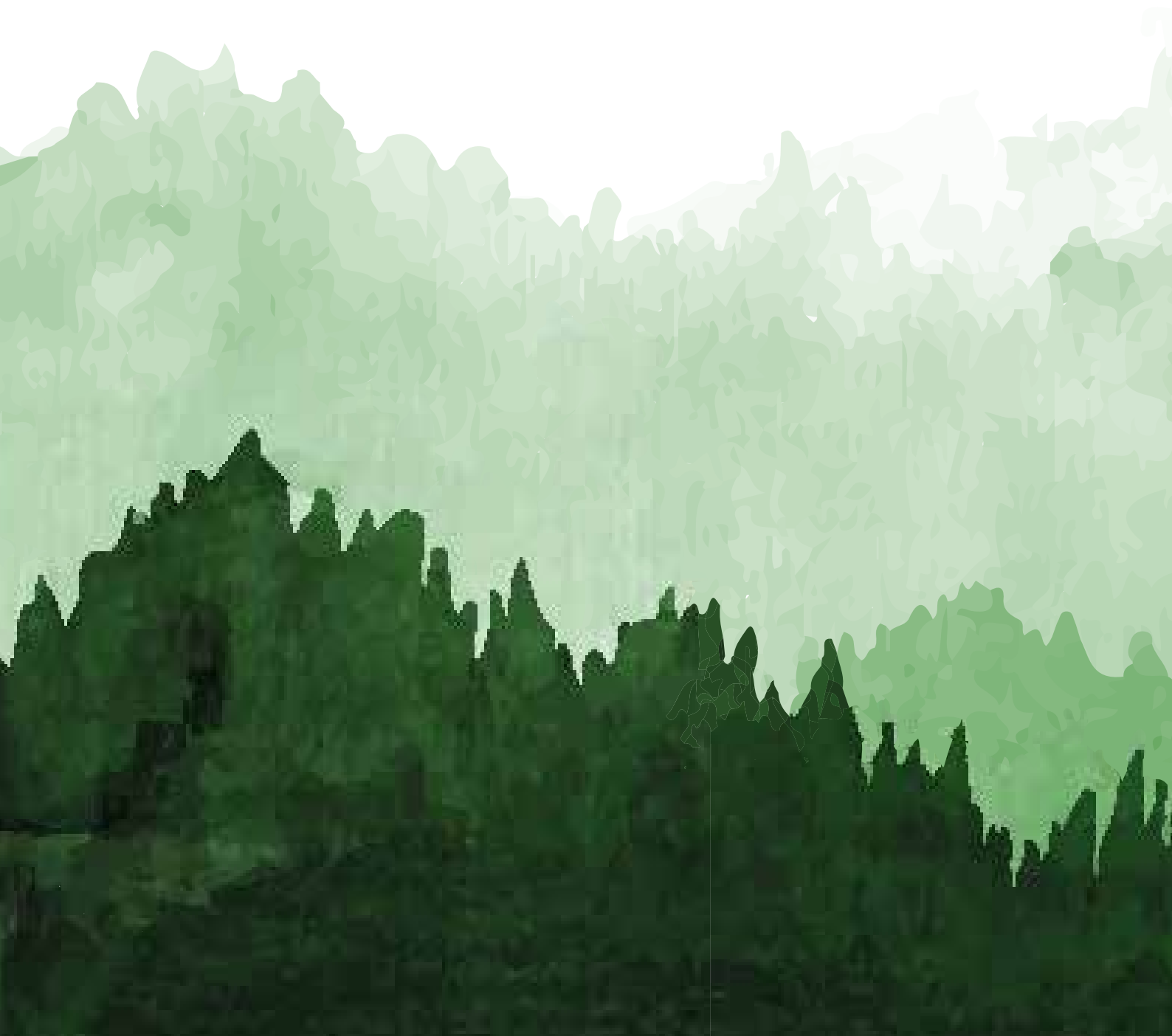
1. Mental Health Epidemiology across the Life Span
2. Depression and Deliberate Self-Harm
3. Mental Health and Well-Being in Work-place Settings
4. Human Rights and Combating Stigma and Social Exclusion

EBC had supported the project objectives as well as work of the EERs in a capacity of associated partner.

Furthermore, we have continued our involvement in the Innovative Medicines Initiative (IMI) funded project AETIONOMY, tackling the challenge of classifying neuro-degenerative diseases by contributing to the works of the Legal and Ethical Advisory Board during the project's meetings in 2017.



# ADVOCACY & OUTREACH



## Visibility

In 2017, 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.

As in 2016, EBC took part in a high number of meetings not only with Members of the European Parliament and representatives from the European Commission (particularly DG SANTE & DG RTD), but also other powerful bodies in the healthcare world, such as the World Health Organization and the Organization for Economic Co-operation and Development (OECD).

Furthermore, EBC maintained its influence at the level of the EU Council by engaging with EU Permanent Representations from Malta and Estonia, with the Value of Treatment closing conference hosted under the auspices of the Maltese EU Presidency.

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

## #ILoveMyBrain

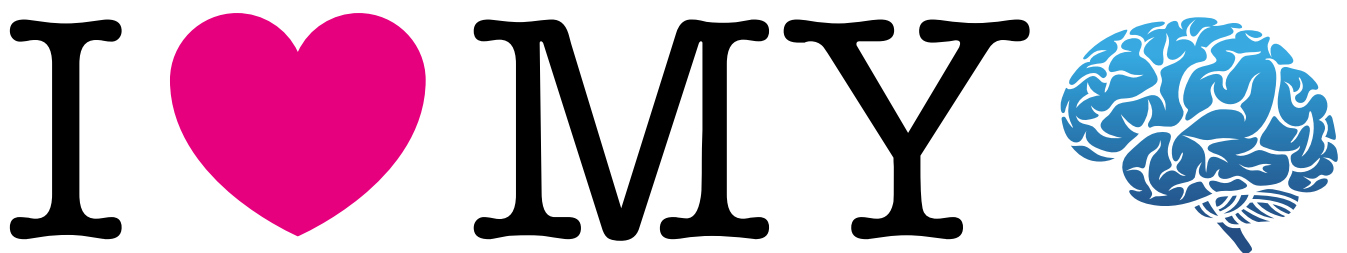
EBC's **I Love My Brain** campaign was officially launched at the Atrial Fibrillation-Related Stroke Workshop on the 25<sup>th</sup> January 2017.

The #ILoveMyBrain logo is 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.

It's with that thought – "I Love My Brain", that researchers, patients, carers, medical professionals, politicians, journalists are all working to reduce the prevalence of brain disorders. Although our projects vary and our focus is on different conditions, we believe that we can all identify with #ILoveMyBrain.

With a 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 welcomed and encouraged all working in brain health to headline their work - fundraisers, policy events, publicity campaigns, research projects, health promotion programs; in government, hospitals, universities, schools and community centres - with the logo.





## AF-Related Stroke Workshop, 25 January 2017

On 25 January 2017, EBC and MEP Aldo Patriciello (Italy), in close partnership with the European Stroke Organization (ESO), EAN, Atrial Fibrillation Association and Arrhythmia Alliance, hosted an AF-Related Stroke Policy Series Workshop in the European Parliament in Brussels - the first event of the I Love My Brain campaign series. Moderated by journalist Peter O'Donnell, the workshop focused on highlighting the importance of pre-screening and early detection of AF to reduce the threat of stroke and featured expert speakers in both AF and Stroke.

As 18% of strokes are associated with Atrial Fibrillation - the most common heart rhythm disturbance - the early detection of previously unknown arrhythmias has proven to enable patients to receive timely and effective diagnosis and treatment in order to avoid possible future onset of stroke.

Speakers included an inspiring testimonial from a Stroke Survivor with aphasia and his journey as a Stroke Ambassador, a presentation on the burden of Stroke, Atrial Fibrillation as presented by a Cardiologist and details on the AF awareness campaign Know Your Pulse.

This AF-related stroke workshop was the last of the workshop series created, with support from the Pfizer-BMS Alliance, under EBC's Year of the Brain, which aimed to highlight the importance of screening for AF, provide a forum for open discussion of all stakeholders in the issue, encourage the placement of regulations and guidelines, recognize stroke as a social and economic burden, and raise public awareness of the prevalence of Atrial Fibrillation, and the easy yet vital screening methods that exist to reduce the threat of stroke.



Peter von Koskull,  
Stroke Survivor



Opening remarks and  
welcoming of guests  
and two panels



Simulator arm used  
to demonstrate how  
to properly identify a  
pulse and to perform a  
pulse check on yourself  
(thanks to Aivoliitto, the  
Finnish Brain Association)



Pulse checking device  
linked to smartphone  
that is able to identify AF  
(thanks to the Arrhythmia  
Alliance)

# #ILoveMyBrain


## #ILoveMyBrain Official Launch – Thunderclap & Valentines competition

The #ILoveMyBrain awareness campaign was officially launched on Valentine's Day, 14 February 2017, through two social media campaigns. The general public was incentivized to get involved in a Twitter competition to win a box of chocolates just in time for Valentine's Day, answering a question daily and retweeting with the hashtag #ILoveMyBrain.

Furthermore, all stakeholders were asked to get behind #ILoveMyBrain by supporting the "Thunderclap" campaign to help spread the logo and message even further across Twitter, Facebook and Tumblr before the Valentine's Day launch.



**"It's time we show our #brains some #love.  
#ILoveMyBrain because #BrainHealth  
matters to us all. <http://thndr.me/ZW22lp>"**

 **European Brain Council** EMBED </>

**SUPPORTERS**  
**144 of 250**  
58% of goal supported

**SOCIAL REACH**  
**244,054**  
People

**TIME LEFT**  
**22 days**  
Ends Feb 14, 11:00 AM CET

Support **European Brain Council** in sharing this message.

support with  
**FACEBOOK**

support with  
**TWITTER**

support with  
**TUMBLR**

We will post this one-time message to your account on  
**February 14 at 11:00AM CET.** [About Support & Privacy](#)

## Brain Tumour: Research and Societal Need

On 27<sup>th</sup> June 2017, EBC Executive Director Frédéric Destrebecq set the scene and took part in a panel discussion on brain tumours in the European Parliament. This seminar, hosted by MEP Neena Gill (S&D, UK) aimed to disseminate knowledge about the problems that face patients with brain tumours, their families and carers to policy makers and other influencers in Europe and to unite European scientists, clinicians, brain tumour patients and policy makers in the fight to improve outcomes in this difficult-to-treat group of tumours.



## EP Event: Can Real World Data Advance Equity of Health Care in Europe?

EBC was happy to support, under the #ILoveMyBrain series, an event organized by the European Multiple Sclerosis Platform (EMSP) in the European Parliament on 7<sup>th</sup> March 2017. The event, hosted by MEP Cristian Buşoi (EPP, Romania), addressed a 'Brain Health' policy initiative driven by health care providers, health economists and patient advocates as well as how real-world data could become the co-driver of regulatory and reimbursement decisions for the benefit of patients and society.

People with Multiple Sclerosis (MS) living in the European Union could receive timelier access to safer and more efficient therapies and could become important partners in the regulation and pricing of medicines. The main conclusion of the day was that the key to turning these possible scenarios into reality is the better exploitation of so-called Real-World Evidence (RWE) data.





## #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, members of the EBC team took part in the Hivernales de Bruxelles 10k run, as well as in the Hunger Race, a 20 or 40k trail run, 7k kayak and obstacle course event. Furthermore, to celebrate the successful launch of the Value of Treatment white paper on the 22<sup>nd</sup> June, the EBC team took part in a fun walking history and cultural tour & quiz of Brussels the next day - an exercise for both the body and the brain!

The team hopes to once again take part in the Brussels 20k in 2018.



Stephanie volunteers to help Tadeusz (EBC Brussels Office) give an Acro Yoga demonstration



EBC team ready to start the walking tour of Brussels



Hivernales de Bruxelles 10k run.



Horseback riding counts, too!

## WHO World Health Day - EBC Joint Statement on Depression

Every year on 7 April, World Health Day is celebrated to mark the anniversary of the founding of the World Health Organization. The day provides an opportunity to mobilize action around a specific health topic of concern to people all over the world, and this year the focus was placed on depression.

In 2017 the one-year campaign began on 10 October 2016, World Mental Health Day, and sought to raise awareness on depression and encourage more people with depression, in all countries, to seek and get help.

On occasion of the WHO World Health Day recognizing a mental health issue, EBC took the opportunity to release a Joint Statement in partnership with its mental health-related member organizations, declaring a European Depression Challenge, to "Reduce the rate of untreated depression to less than 10% by 2030". This called on all European people and governments to pledge their commitment and invest the necessary resources towards meeting the challenge.

To maximize coverage on social media channels, EBC also collected short video messages from representatives of our members working in psychiatry and mental health calling for better awareness and support of those living with depression and other mental health conditions.



# Suicide Prevention Working Group

On 10 February 2017, EBC convened a group of experts in suicidology in an effort to publish a Policy White Paper with clear recommendations to EU institutions and member states in the domains of suicide prevention: identification of risk factors for suicide, protection of people at risk of suicide, social and therapeutic measures to be implemented to reduce the morbidity and mortality of suicide and information and measures of education to be disseminated within the European population.

The group focused on gathering and summarizing the current data and state of evidence regarding various aspects of suicide, including the epidemiology of suicide in European countries, social aspects of suicide, efficient therapeutic measures currently implemented and best ways and means to educate the general population regarding suicide risk (to name a few). All of this research was then used to produce short white papers for dissemination, of which a one-pager of Key Facts & Figures was disseminated widely to mark World Suicide Prevention Day on 9 September.



## Suicide in Europe: Facts and Recommendations

World Suicide Prevention Day - 10<sup>th</sup> September 2017

### The Facts

#### 1. The epidemiology of suicide in European countries

More than 150,000 people in Europe die by suicide every year. **Suicide is, in some European countries, the leading cause of death amongst young people aged 15-24 years.** The standardized death rate for intentional self-harm in the EU28 is higher for persons aged 65 and over than for younger people. **Globally, the countries of Eastern Europe have the highest suicide rates in the world (21.35/100,000).** It should be noted that the comparability of data on intentional self-harm is limited due to underreporting of suicides in certain EU Member States.

#### 2. Suicide Risk Factors include:

**History and family history of suicide; stressful life events and discrimination; somatic comorbidity; psychiatric comorbidity.** In adolescents: **pathological internet use, school bullying, domestic violence, overweight, depression, anxiety, drug and alcohol abuse.**

**Protective factors include:** cognitive flexibility coping strategies; **healthy lifestyle (good diet, good sleeping patterns, active life including physical exercise); social and family support.** **School-based protective factors include:** school safety, relationships with caring adults at school, school connectedness.

#### 3. Social aspect of risk: Suicide at the workplace

High occupational suicide rates are often linked to people working in **protective service occupations** (e.g. law enforcement officers and firefighters), those with easy occupational **access to lethal means** (e.g. doctors, pharmacists, police, farmers), and in **jobs with high stress and low control.**

#### 4. Warning signs of imminent suicide

**Identifying "warning signs" increases the overall number of suicidal individuals accessing care.** Among the most important ones are: preparation behaviours, rehearsal behaviours, risk-taking behaviours, observable and objective signs of rage/anger, withdrawal, anxiety/agitation, insomnia/nightmares, substance use, dramatic mood changes and explicit communication of suicidal thoughts.

### The Recommendations

#### 1. Prevention of suicide through Education and Training

**Education and training programs have been successful in reducing suicidal behaviour, improving the care of at-risk populations and preventing suicide.** Campaigns promoting help-seeking should target personal attitudes towards mental health stigma. School-based universal mental health promoting programs significantly decrease suicidality and therefore are an opportunity to target youth for suicide prevention. Gatekeeper training programs and education of general practitioners and other health care providers is another key area for suicide prevention.

#### 2. Prevention of suicide through digital tools

This includes three different approaches: Monitoring through **"Facebook" and other channels** on the internet for words or sentences that might indicate suicide risk. **Recruiting social media** to help in cases where suicide issues are surfaced. Creating a **targeted patient WhatsApp group** that focuses on support and help for a specific patient.

#### 3. Psychosocial interventions

These are better achieved through Collaborative Assessment and Management of Suicidality (CAMS) programs, along with the implementation of active **outreach means: sending postcards, telephone calls, and/or home visits.**

#### 4. Psychotherapeutic interventions

Considered together, **different psychotherapies seem to be efficacious in the reduction of both suicide attempts (SA) and non-suicidal self-injuries** which are risk factors for subsequent SA. Interventions directly addressing suicidal thoughts and behaviour during treatment are effective immediately and in the long term on SA and suicide death, whereas treatments addressing symptoms indirectly associated with suicide (e.g. hopelessness, depression, anxiety, quality of life) are only effective in the long term.



#### 5. Pharmacotherapeutic Intervention

Randomized controlled trials show that **lithium is effective in reducing the risk of suicidal behavior in people with mood and bipolar disorders.** **Clozapine** in comparison with other dopamine and serotonin-receptor antagonists has demonstrated its **anti-suicidal effect in schizophrenia.** Initiation of treatment with **antidepressants is not associated with an increased risk of suicide**, however, youth should be followed carefully. Continuation of pharmacotherapy for depression is associated with a reduced risk of suicide. Moreover, an evaluation of the **relationship between changes in the prescription of drugs for depression and changes in suicide prevalence found a clear inverse correlation** in 29 European countries. **Ketamine** shows promising results but effects on suicidal ideation longer than a few days have not yet been demonstrated.

#### 6. The role of patient organization

**Patient organizations can play a major role in supporting people with poor mental health and at high risk of suicide.** Patient organizations can provide the **additional support post-diagnosis** with health education (or "psycho-education"), and provide a **sense of community and peer support** that many high-risk suicidal patients lack. Awareness campaigns aimed at the general public and policymakers for healthcare systems can **educate and reduce stigma and lack of knowledge in relation to mental health problems.**

#### 7. The role of family organizations

Family members are often in a **position to notice the risk factors** but may not always be aware. Suicide causes profound and long lasting psychological trauma and, on average, **a single suicide affects a minimum of six persons.** Family members and friends **require support.** A **no-blame approach** towards family members is essential. Family members should have **access to information, training, quality consultation services, and to local support groups.** Family organizations can play a similar role to that of patient organizations, as they can provide a **community and further support** for those affected by suicide, as well as **help educate the general public about risk factors, preventive measures, and the societal impact of suicide.**

#### 8. Relationships with the media

**Media reports which glorify, romanticize, or portray suicide as a normal response to stress, may encourage suicides, especially among vulnerable individuals.** WHO has introduced a set of guidelines for responsible media reporting which are detailed in the joined document.

#### Suicide Prevention Working Group Members:

Courtet R, European Psychiatric Association (EPA) and World Federation of Societies of Biological Psychiatry (WFSBP)

Iwari A, European Federation of Associations of Families of People with Mental Illness (EFAFMI)

Karkainen H, Global Alliance of Mental Illness Advocacy Networks Europe (GAMIAN-Europe)

Saracoponne M, European Psychiatric Association (EPA)

Wasserman D, European Psychiatric Association (EPA) and the European College of Neuropsychopharmacology (ECNP)

Zohar J, European College of Neuropsychopharmacology (ECNP) and the Expert Platform on Mental Health - Focus on Depression

Coordination: Boyer P, European Brain Council (EBC) and European Psychiatric Association (EPA)

Project Manager: Kanner S, European Brain Council (EBC)

Under the auspices of the European Brain Council (Nuff D, President)



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## Ensuring the safe prescription of medicines off-label in Europe - Roundtable discussion

The European Brain Council (EBC) hosted the highly insightful roundtable discussion *"Ensuring the safe prescription of medicines off-label in Europe: what role for the European Union?"* on the 10 July 2017. This event brought together over 30 stakeholders to discuss challenges related to the off-label use of medicines in the EU as well as the outcomes of the "Study on off-label use of medicinal products in the European Union" that was published by the European Commission in February 2017.

Off-label use is the practice of using a medicine outside its authorised indication, for another patient group or in a different dose. The use of medicines off-label is often a necessity in areas of unmet medical need but also poses challenges in terms of patient safety, professional liability and therapeutic innovation. The manner in which countries deal with the off-label use of medicines is currently not harmonised across the EU.

In order to raise awareness of the importance of defining a clear approach to off-label use across Europe, EBC as well as 10 other European and national organizations have endorsed the GOLUP-declaration which calls on the European Medicines Agency (EMA) and national regulatory bodies to adopt guidelines on the practice of using medicines off-label. At the event, professor Marc Doods, the main author of the GOLUP, presented the revised GOLUP principles, which were written in cooperation with experts from the paediatric and psychiatrist communities in 2017. The declaration found support among various stakeholders that attended the roundtable discussion.

Speakers that contributed to the event included:

- Frédéric Destrebecq, EBC Executive Director
- Aude L'hirondel, Unit B5 - Medicines: policy, authorisation and monitoring, DG Sante, European Commission
- MEP Lieve Wierinck (BE, ALDE)
- MEP José Inácio Faria (PT, EPP)
- Marc Doods, Senior orphan drug pharmacist, University Hospitals Leuven, and main author of the GOLUP Declaration
- James Killick, Lawyer and regulatory expert, White & Case LLP
- Lucia Ruggeri, Coordinator, TEDDY Network Scientific Secretariat



## Ensuring the safe prescription of medicines off-label in Europe - Roundtable discussion

The participants provided EU decision-makers with suggestions on how existing challenges in the domain of off-label use can be addressed. Additionally, a call for EU guidance on the practice of off-label use came out strongly from GOLUP signatories and other stakeholders in the room.

The following organizations have joined as co-signatory of the GOLUP-declaration:

- European Federation of Neurological Associations (EFNA)
- European Multiple Sclerosis Platform (EMSP)
- European Medical Association (EMA)
- European Brain Council (EBC)
- European Alliance for Access to Safe Medicines (EAASM)
- European Alliance of Restless Legs Syndrome (EARLS)
- European Myalgic Encephalomyelitis Alliance (EMEA)
- European Parkinson`s Disease Association (EPDA)
- Associazione Italiana Miastenia e Malattie Immunodegenerative (AIM)
- European Association of Myasthenia Gravis Patients' Associations (EuMGA)
- The Encephalitis Society



## Trimbos joint statement for MH research investment

EBC, alongside member organisations EPA, ECNP, GAMIAN-Europe and EUFAMI, endorsed a new Joint Statement on the need to further invest in mental health research and the implementation of a European Partnership on mental health and wellbeing written by the Trimbos Institute.

As written in the introduction of the statement, “mental ill health leads to huge personal and economic costs for European individuals, communities and economies. The European Commission, EU Member States, WHO, and OECD recognise the need to address this negative impact of mental ill health. A “Mental Health in all Policies” approach is required in order to ensure social inclusion and financial sustainability. However, the lack of parity of esteem and disparity of funding between mental and physical health has been a huge barrier. Mental health research and the implementation of research outcomes are disproportionately underfunded. [The] Joint Statement makes a case for investing in mental health research and implementation.”

## EBC advocacy on e-health and digitalization

Information and communication technologies (ICT) have developed rapidly in recent years and provide opportunities for addressing challenges that brain disorders impose on European societies. The Policy White Paper on the “Value of Treatment (VoT) for Brain Disorders in Europe” highlighted the importance of using e-health tools to overcome the treatment gaps associated with 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. Given that there is currently no disease modifying treatment to cure many mental and neurological disorders, which are likely to affect more than 1 in 3 Europeans, it is essential that the potential of digital therapeutics and e-health solutions is further explored by policy-makers and scientific communities.

EBC firmly believes that the future of brain health can only be achieved by means of well-designed digital health technologies, and aims to join the forerunners in the digital movement. In this regard, EBC supported the drafting of the Digital Health Society Declaration, a statement launched by the Ministry of Social Affairs of Estonia that expresses challenges for health data sharing and digital health deployment and contributed to the public consultation on the transformation of health and care in the digital single market, launched by the European Commission in July 2017.

## Digital Therapeutic Partnership (DTP) meeting, London 14 July & EU Presidency Estonia - e-Health conference, Tallinn 16 October

Digital health is a strategic topic and this DTP meeting together with industry partners was an opportunity to present the VoT project conclusions and to position EBC in the discussions on the need for digital health care, e-health tools such as mental health apps and wearable sensors having the potential to improve the prevention and management of brain disorders. Furthermore, EBC was invited to speak on the digital opportunities for brain health at eHealth Tallinn 2017: 'Health in the Digital Society. Digital Society for Health', organised by the Estonian Ministry of Social Affairs as part of Estonia's Presidency of the Council of the European Union, a high-level conference addressing how digital technologies and the wider use of health data are changing our lives and the ways of healthcare.



Executive Director Frédéric Destrebecq  
speaking at eHealth Tallinn 2017

## BrainxHealth: The Digital Future is on its way, Brussels 22 November 2017

EBC held an event dedicated to eHealth at the European Parliament, "Brain Health: The Digital Future is on its way" on 22 November to discuss the benefits of e-health and m-health solutions. Co-hosted by MEPs Michal Boni (EPP) and Carlos Zorrinho (S&D), the successful event brought a packed room of various stakeholders together and spoke to the true opportunities provided by digitalization of healthcare, which EBC is keen to support and develop into an integral part of its advocacy strategy.

The event was the beginning of a new collaboration with Phrenos and Tipik to debut their xHealth initiative, focused on building and supporting citizen-driven demand in eHealth, getting away from a "task-focused perspective" and rather focusing on a systemic approach (PX paradigm).

The workshop aimed to answer the overarching questions: 'what are the benefits of digital technology for healthcare for the brain?' and 'how do we ensure these benefits reach the people who need it most?', and brought together an excellent panel of speakers that included both host MEPs, EBC President Prof David Nutt, Elen Ohov (Counsellor for eServices (Health and Social Affairs) at the Permanent Representation of Estonia to the EU), Magda Chlebus (Director of Science Policy at the European Federation of Pharmaceutical Industries and Associations - EFPIA), Monika Benson (Executive Director of Dystonia Europe), Prof. Giuseppe Carrà (University of Milano Bicocca), Kim Baden-Kristensen (Founder & CEO of Brain+ & Digital Therapeutics Partnership), Thomas Lethenborg (CEO & Partner of Monsenso) and Deepak Tawari (Founder & CEO of Privately).



"Brain Health: The Digital Future is on its way",  
European Parliament



Co-host MEPs Carlos Zorrinho and Michal  
Boni, EBC President Prof. David Nutt



Full room of attendees and many more tuned in to the Facebook Live stream

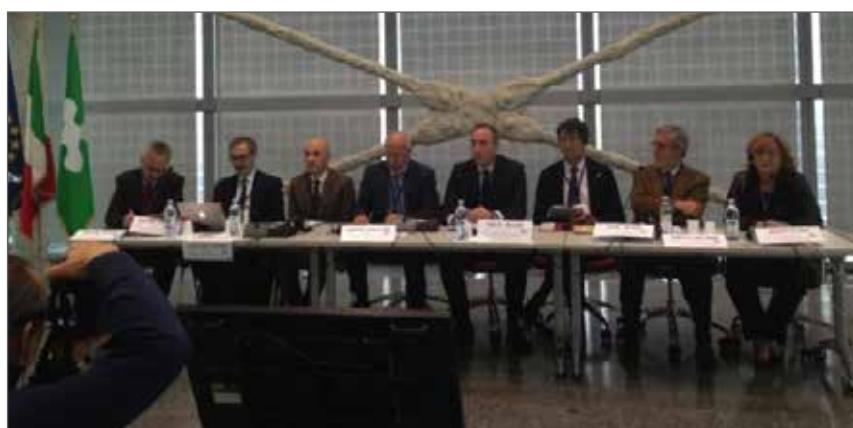


## Pre-G7 health ministries event

Under the auspices of EBC, the World Health Organisation, the Italian Ministry of Health and the Lombardy Region, the IRCCS Foundation "Carlo Besta" Neurological Institute held the event *"Innovation and Research for Healthy Ageing: new questions for research and new answers from innovation"* in Milan on 4 November 2017, as a complementary event to the G7 Ministries of Health meeting also taking place.

The main aim of the event was to support the G7 Ministries of Health to identify the most important challenges and the key questions that need answering to improve healthy ageing worldwide, and featured an agenda full of high level international speakers.

EBC Executive Director Frédéric Destrebecq chaired the session on "Gaps that need to be filled: the role of Research", which also includes presentations from Monica Di Luca, EBC Vice-President, on "Brain research: the key for healthy ageing" and Matilde Leonardi, EBC-WHO Liason, on "Research supporting policy development and innovation".



Prof. Matilde Leonardi, EBC-WHO Liason



**COLLABORATION**

## 3<sup>rd</sup> Academy of National Brain Councils

The 3<sup>rd</sup> Academy of National Brain Councils was held again in Brussels this year, kicking off with the Meeting of the MEP Interest Group on Brain, Mind and Pain, and the Interest Group on Mental Health, Well-being and Brain Disorders Value of Treatment Parliamentary launch event on Early Intervention.

Representatives from 10 countries with established or upcoming NBCs attended to share their work, brainstorm together and learn from guest speakers. The guest speakers included:

- Ortwin Schulte, Head of Unit Health Policy, German Permanent Representation to the EU – The role of the EU in health policy and in health system development
- Carla Finocchiaro, CF Consulting Director – Participation in EU funded projects
- Philippe Amouyel, Chair of EU Joint Programme on Neurodegenerative Disease Research
- Camille Bullo, European Patients Forum Director of Operations & Engagement – Toolkit on Building National Coalitions of Patient Organizations
- Donna Walsh, European Federation of Neurological Associations (EFNA), Executive Director – Training Initiatives for Neurology Advocates [TINA]
- Nada Sirotic, Research, Innovation, Space Attaché in Permanent Representation of the Republic of Croatia to the EU

Each NBC had a chance to present their ambitious work, experience, successes, strategies & paths toward establishing National Brain Plans within their individual countries.

Nearly 30 countries have formed, or are in the process of forming, National Brain Councils and National Action Groups which are independent but aligned with the main goals of the EBC.





# ADHD Expert Policy Paper

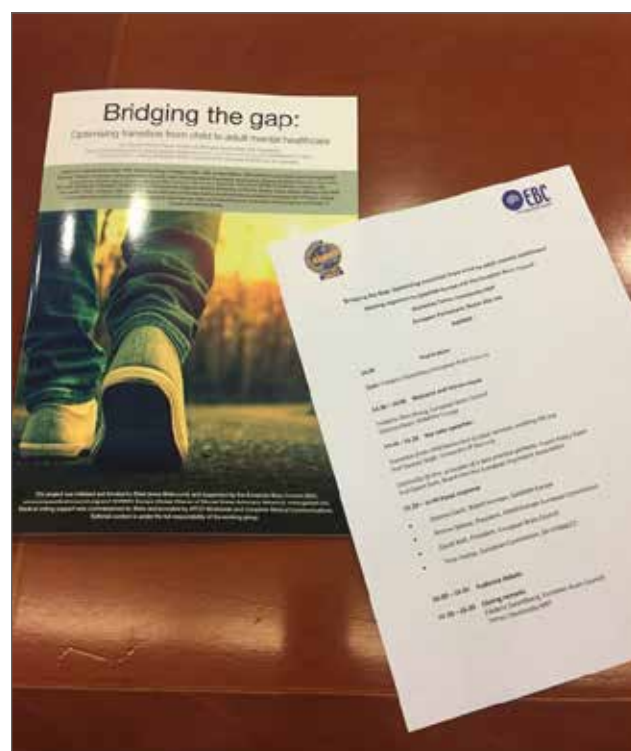
On 11 July 2017, EBC & GAMIAN-Europe, with support from Shire, co-organised the working meeting “Mental Health & Transition of Care: A best practice pathway for ADHD across the lifespan” in the University Foundation. The objectives of the meeting were to bring together key stakeholders with an interest in improving the state of mental health in Europe, with a particular focus on the transition of care from childhood to adulthood in mental health services and to discuss and agree on principles and recommendations for health systems in order to drive improvements in the transition pathway and ultimately the long-term outcomes for patients with ADHD and mental health conditions.

The meeting brought together experts in the field, all who ultimately contributed to the production of an Expert Policy Paper, which highlights the gaps in care for Europeans transitioning from child to adult mental health care services, and calls on policymakers to support improvements to healthcare systems. Furthermore, it suggests simple measures that aim to ensure young adults, who may require continued care, receive the support they need.

The paper was launched in the European Parliament on 21 November 2017, hosted by Mr. Tomáš Zdechovský MEP, with presentations from various authors of the expert policy paper.



Launch of the expert policy paper in the European Parliament - Prof Swaran Singh (University of Warwick, UK) gives keynote speech on 'transition from child/adolescent to adult services: avoiding the gap'



Launch of the expert policy paper in the European Parliament



# ADHD Expert Policy Paper

*The Expert Policy Paper has been authored by (in alphabetical order):*

*Philip Asherson (King's College London, UK);*

*Andrea Bilbow (ADHD Europe);*

*Kate Carr-Fanning (ADHD Europe);*

*Frédéric Destrebecq (European Brain Council);*

*Geert Dom (European Psychiatric Association);*

*Silvana Galderisi (European Psychiatric Association);*

*Dolores Gauci (GAMIAN-Europe);*

*Marc Hermans (UEMS Section of Psychiatry);*

*Tony Lloyd (ADHD Foundation, Liverpool, UK);*

*Ann Little (European Federation of Neurological Associations);*

*Fulgencio Madrid (University of Murcia, Spain);*

*Kuben Naidoo (Mersey Care NHS Trust, Liverpool, UK);*

*J. Antoni Ramos-Quiroga (Universitat Autònoma de Barcelona, Hospital Universitari Vall d'Hebron, Spain);*

*Swaran Singh (University of Warwick, UK);*

*Donna Walsh (European Federation of Neurological Associations);*

*Spyros Zorbas (European Federation of Associations of Families of People with Mental Illness)*



L-R: Executive Director Frédéric Destrebecq; Tomáš Zdechovský MEP; Dolores Gauci, GAMIAN-Europe; Prof Geert Dom, EPA; Andrea Bilbow, ADHD-Europe; Terje Peetso, European Commission DG CONNECT; Prof Swaran Singh, University of Warwick; EBC President Prof David Nutt

## Brexit & Healthcare: Prioritising patient safety and public health across Europe post-Brexit

This year marked the start of the Brexit-negotiations. Given that the UK significantly contributes to regulating and approving medicines in the EU, the UK's departure from the EU might have significant consequences in terms of patient safety. Additionally, the UK has the highest number of phase I clinical trials across the EU, and therefore Brexit might affect access to innovative treatments for people living with brain disorders.

In view of the challenges presented by Brexit, EBC endorsed the statement "Prioritising patient safety and public health across Europe post- Brexit" which was officially launched on the 7<sup>th</sup> of December 2017. This statement provides a number of concrete policy recommendations to ensure patient safety and highlights the importance of prioritizing the interests of patients, quality of care and of medical research in the Brexit negotiations.

Policy-makers are called upon to:

- ensure that EU27 and UK patients continue having access to life-saving drugs and medical technologies, and early access to new health technologies post-Brexit
- ensure the EU remains a world class hub for research and collaboration post-Brexit
- ensure that EU27 and UK patients continue to receive the best possible care, wherever they need it
- ensure that public health for all EU and UK citizens is maintained post-Brexit
- ensure that EU27 and UK health professionals continue to benefit from mutually beneficial training and education opportunities, automatic recognition of their qualifications, and can continue to provide healthcare services to EU27 and UK patients

In order to raise awareness of its recommendations, the statement was sent to the EU Health Ministries, the Permanent Representations to the EU and the Taskforce on Article 50 negotiations with the UK. The supporters of the statement received an official response from Deputy Chief Negotiator Ms Sabine Weyand in which she underlined the importance of taking the interests of patients as well as the need to preserve a high level of protection of human health into account. Additionally, national brain councils were called upon to contact their national Health Ministries and urge them to support the statement.

The statement is currently supported by 14 organizations, among which EBC, EFNA and FENS.

# Responsible use of Animals in Research

In the European Union, animal research is governed by the Directive 2010/63/EU on the protection of animals used for scientific purposes. It is anchored in the principle of the Three "R's": Replace, Reduce and Refine the use of animals in the scientific research.

Over the past years there has been a number of initiatives to counteract the current legislation, with the latest being the European Citizens' Initiative "Stop Vivisection", submitted to the European Commission in 2015. It called for "the European Commission (EC) to abrogate directive 2010/63/EU and to present a new proposal that does away with animal experimentation".

EBC has joined a wide coalition of organizations expressing support in the current legislation and become an active member of an informal body European Life Science Alliance (ELSA). ELSA is a collaborative platform for organizations across Europe who have an interest in a scientifically and ethically justified use of animals in biomedical research.

In its response, the Commission rejected the idea of abrogating the directive, nonetheless announced taking extra steps to assess if there are means to improve implementation of the directive. A high-level conference was organized in December 2016 to discuss how to exploit the advances in science for the development of scientifically valid non-animal approaches and advance towards the goal of phasing out animal testing.

In 2017 the Commission published report reviewing the current directive.

The major conclusions were:

- The timing of the review of the Directive's implementation is premature
- The majority of stakeholders consider the Directive to be relevant and necessary for creating a level playing field within the EU and achieving the animal welfare objectives and standards
- No amendments were proposed at that stage
- No phasing-out timetable for the use of non-human primates was proposed

To support the EC further, EBC has also endorsed in November 2017 a call to action, orchestrated by Federation of European Neuroscience Societies, for world leading, innovative and responsible medical research in Europe.

EBC's firm stance is that while animal research has many limitations when translating to humans, and animal models may not always reliably reproduce the human condition, they provide a unique window into nervous system research and have generated important directions for future human research. Exploring alternatives needs to be continued and prioritized, at the same time stopping animal research at this point would have a catastrophic effect on the development of the medical sciences, and in particular the neurosciences.

# Scientific Congresses

## EPA

The annual European Psychiatric Association (EPA) congress, the 25<sup>th</sup> European Congress of Psychiatry, was held on 1-4 April in Florence, Italy. Every year, EPA hosts this major meeting of international psychiatrists dedicated to promoting European psychiatry and to improving mental health around the globe. The theme of the 2017 congress was “Together for Mental Health”, emphasizing the current efforts to affirm that mental health is an essential component of public health – with a significant impact on the human, social and economic capital of all European countries.

This year’s Congress also aimed to strengthen the dialogue between neurosciences and social sciences to help overcome the traditional separation between the domains.

EBC was present in the exhibition hall, handing out information on the Value of Treatment, the work of the Suicide Prevention Working Group, the Joint Statement on Depression to mark WHO World Health Day, Not Myself Today and the work of EBC as a whole. As shared in the Value of Treatment section earlier in the report, EBC also held a joint EBC-EPA Symposium presenting the work of the Value of Treatment’s Schizophrenia working group.



<http://epa-congress.org/2017/useful-links/promotional-toolkit#.WnCWaKinGUi>





# Scientific Congresses

## EAN

The 3<sup>rd</sup> Congress of the European Academy of Neurology (EAN) took place in Amsterdam, the Netherlands from 24-27 June 2017. 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 unraveled, and current treatment options are extending.

EBC and the Value of Treatment project were included in the opening address of Prof. Günther Deuschl, President of the European Academy of Neurology. A joint EBC-EFNA booth was also set up in the exhibition hall, where EBC colleagues introduced & handed out Value of Treatment white papers and the #ILoveMyBrain selfie wall was a popular destination for congress attendees.



# Scientific Congresses

## ECNP

The 30<sup>th</sup> Annual ECNP Congress took place on 2-5 September 2017 in Paris, France. The congress attracts up to 6000 delegates, and is the largest European congress of applied and translational neuroscience. Held in autumn every year, the Congress brings together a vibrant group of psychiatrists, neuroscientists, neurologists and psychologists from around the world to discuss the latest developments in the science and treatment of brain disorders. With around 6000 participants, the ECNP congress is Europe's premier showcase for new research, treatments and technologies in applied brain science.

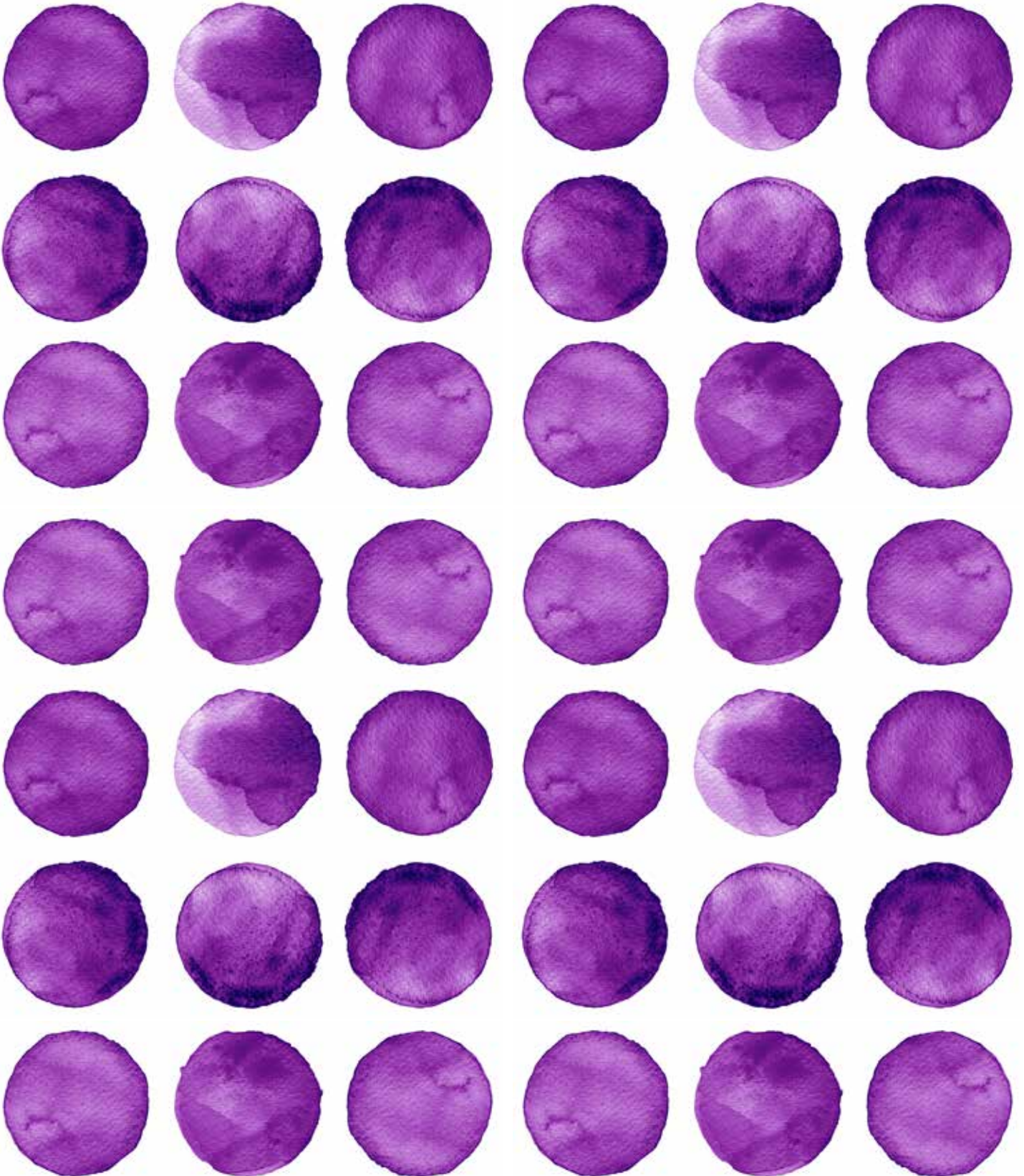
EBC was present with an exhibition booth, and Prof. David Nutt introduced the Value of Treatment project through the Lundbeck Institute Campus - a website focused on fostering disease awareness and the impartial provision of clinically relevant information and informed opinion - which now features the findings of the Alzheimer's, Schizophrenia and Parkinson's working groups.







# EBC MEMBERS & PARTNERS





## Full Members



The **European Federation of Neurological Associations** (EFNA) brings together European umbrella organisations of 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 organisations, placing the patient at the centre of all issues of EU healthcare debate. The organisation 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 **European Academy of Neurology** (EAN) is a non-profit organisation 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 College of Neuropsychopharmacology** 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



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



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



The **Pan European Regional Committee** (PERC) of the **International BrainResearch 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 PanEuropean 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.

[ibro.info](http://ibro.info) / @ibroSecretariat

## Associate Members & Observers



The **Brains for Brain** (B4B) aims to develop new and innovative therapeutic strategies to cross the Blood-Brain Barrier, a capillary system which shields and defends the CNS from circulating neurotoxin compounds. B4B mission consists of the promotion of an International Network of health professionals in rare disorders, specifically in the field of rare neurological pediatric diseases.

[www.brains4brain.eu](http://www.brains4brain.eu)



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.

[eans.org](http://eans.org) / @EANSonline



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.

[www.ifcn.info](http://www.ifcn.info)



The **European Stroke Organisation** (ESO) is a pan-European society of stroke researchers and physicians, national and regional stroke societies and lay organisations that was founded in December 2007. Their aim is to reduce the incidence and impact of a stroke by changing the way that stroke is viewed and treated.

[eso-stroke.org](http://eso-stroke.org) / @ESOstroke



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.

[eufami.org](http://eufami.org) / @EUFAMI



The **Federation of the European Societies of Neuropsychology** (ESN) aims to further scientific and professional issues within the field of neuropsychology by developing European programmes of clinical and experimental neuropsychological research as well as pre- and postgraduate teaching and to put forward any instances related to Neuropsychology. Such objectives are pursued by holding periodical scientific meetings and such other activities as may be deemed appropriate.

[www.fesn.eu](http://www.fesn.eu)



The **International League Against Epilepsy** (ILAE) is the world's preeminent association of physicians and other health professionals working towards a world where no persons' life is limited by epilepsy. ILAE's mission is to ensure that health professionals, patients and their care providers, governments, and the public world-wide have the educational and research resources that are essential in understanding, diagnosing and treating persons with epilepsy.

[ilae.org](http://ilae.org) / @IlaeWeb



**MQ Health** is a UK-based charity whose aim is to transform mental health and quality of life through research. Their vision is to create a world where mental illness is understood, effectively treated, and ultimately prevented. MQ Health is currently working on numerous research projects to tackle mental illnesses, ranging from anxiety and schizophrenia to depression and OCD.

[mqmentalhealth.org](http://mqmentalhealth.org) / @MQmentalhealth

# National Brain Councils



Belgian Brain Council



Bulgarian Brain Council



Croatian Brain Council



Czech Brain Council



Dutch Brain Council



Finnish Brain Council



French Brain Council



Irish Brain Council



Luxembourg Brain Council



Norwegian Brain Council



Polish Brain Council



Portuguese Brain Council



Serbian Brain Council



Slovenian Brain Council



Spanish Brain Council



Turkish Brain Council



## Industry Partners

abbvie



BIOMARIN



Joining on 1<sup>st</sup> January 2018



# MEMBERS' HIGHLIGHTS

## EFNA'S HIGHLIGHTS OF 2017

The Training Initiatives for Neurology Advocates [TINA] is an EFNA-run programme for neurology patient advocates at both a pan-European and National level. The programme was expanded in 2017 to see four workshops held - a pan-European event in Brussels in May, focusing on **'Effective External Ambassadorship', and National events in Romania ('Science, Storytelling and Social Affairs'), Spain ('Understanding and Influencing Healthcare Decision-Making') and Poland ('How to Become Your Own Advocate')**.

There were a further three meetings of the MEP Interest Group on Brain, Mind and Pain at the European Parliament in Brussels. The group is coordinated by EFNA together with Pain Alliance Europe [PAE]. The topics covered were *'Optimising the European Social Pillar to #MakeWorkWork for those affected by brain disorders and chronic pain conditions', 'The Value of Early Intervention in Brain, Mind and Pain Conditions' and 'Ensuring equitable access to high-quality treatment in brain, mind and pain disorders'*.



Effective External Ambassadorship TINA Workshop – Brussels, May 2017

As part of EFNA's Together Under the Umbrella campaign, organisations and individuals were encouraged to share a photo on social media on World Brain Day (July 22<sup>nd</sup>). To mark the day EFNA recorded a series of interviews with patients/patient advocates from seven different disease areas. You can watch the videos at [www.undertheumbrella.eu](http://www.undertheumbrella.eu)

Speaking on the day, EFNA President, Ann Little said: "By continuing to work together we can maximise the visibility of brain disorders as a whole and ensure we can access the resources required to tackle the enormous burden these diseases pose."



## FENS' upcoming activities in 2018

In collaboration with prominent partners, FENS offers a comprehensive programme for European higher education in neuroscience in 2018.

In July 2018, the FENS Forum 2018 will take place in Berlin, where FENS will celebrate its 20th anniversary. The Forum has an exciting scientific programme, together with the 'Bridging Knowledge Session', special interest events, satellite events, networking events, business meetings and much more.

The European Brain Council will organise a dedicated special interest event on Monday 9 July at noon to discuss its latest strategy for brain research.

## FENS Neuroscience Schools

- **FENS-SfN Summer School 2018:**  
Neuralstem cells, brain organoids and brain repair 3-9 June 2018, University Centre of Bertinoro, Italy
- **FENS-Hertie Winter School:**  
Neural control of instinctive and innate behaviour 6-12 January 2019, Obergurgl, Austria

## The Brain Conferences

- **Computational Neuroscience of Prediction,** 15-18 April 2018, Rungstedgaard, Denmark
- **The Necessity of Cell Types for Brain Function** 7-10 October 2018, Motkes Palae, Copenhagen, Denmark

## The CAJAL Advanced Neuroscience Training Programme

- **Developmental Neurobiology and Pathologies,** 3 - 21 April 2018  
Bordeaux Neurocampus – in partnership with ERA-NET Neuron
- **Neuroinflammation and How to Study It,** 25 June - 7 July 2018  
Bordeaux Neurocampus
- **Behaviour of Neural Systems,** 15 July - 4 August 2018  
Champalimaud Centre for the Unknown
- **Computational Neuroscience,** 12 August - 1 September 2018  
Champalimaud Centre for the Unknown
- **Advanced Imaging Methods for Cellular Neuroscience,** 10 - 28 September 2018  
Bordeaux Neurocampus
- **Linking Neural Circuits and Behaviour,** 8 - 26 October 2018  
Bordeaux Neurocampus

**Full 2018 programme available at [www.cajal-training.org](http://www.cajal-training.org)**

**FENS Forum 2018: Register at [www.fens.org/2018](http://www.fens.org/2018)**

**For more information, please visit FENS website: [www.fens.org](http://www.fens.org)**



The EAN actively contributed in the 2017 activities of the European Brain Council.

EAN contributed to the “Value of Treatment - VOT/cost of non-treatment” project in which 7 out of 9 diseases analyzed are neurological disorders.

Multi-disciplinary teams intensively studied the patients journey (a new concept on how to analyze the burden and quality of diagnosis, therapy and care) in disorders like dementia, epilepsy, headache, multiple sclerosis, Parkinson’s disease, restless legs syndrome, stroke.

The calculation of the costs of non-therapy by the school of economics in London, United Kingdom, revealed amazing numbers. Second to dementia, as the obviously most pressing challenge in Neurology and Neuropsychiatry, Restless Legs Syndrome (RLS) came up equal with stroke, in respect to the costs of non-treatment. The high prevalence of this pain-movement-sleep disorder explains these results.

In addition, EAN reports on its very successful third national conference in Amsterdam with more than 6.000 participants. EAN also has now restructured its activity with regard to European issues by increasing the number of members in the European Affairs sub-Committee from three to five members. In addition one of the vice-presidents in the executive board of the EBC represents Neurology.

EAN has also a seat on the board of the Biomedical Alliance, a lobby group for basic and clinical biomedical science of an important number of medical societies in Europe. In addition, Neurology is well represented at the high level advisory group with the Commissioner for Research and Innovation, Dr. Moedas. Two neurologists sit on the Scientific Panel for Health – Jose Ferro and Wolfgang Oertel.

One of the major goals of the Scientific Panel for Health is to create a European Health Research Council, similar to the very successful structure of the European Research Council. All in all neurology is moving strong, EAN still is a young society but its impact on health policy in Europe increases.





# **STAKEHOLDERS' HIGHLIGHTS**

# MENTAL HEALTH COMPASS

The second Annual EU Compass Forum on Mental Health and Well-being took place in Luxembourg on 8-9 June 2017. The event is organized yearly by a consortium led by the Trimbos Institute in the Netherlands together with the NOVA University of Lisbon, the Finnish Association for Mental Health and EuroHealthNet under the EU Health Programme (2014-2020) in the frame of a service contract with the Consumer, Health, Agriculture and Food Executive Agency (Chafea) acting under the mandate from the European Commission.

The focus of this year's Forum was Mental Health at Work, Mental Health at Schools, and Prevention of Suicide and brought together diverse stakeholders such as policy makers and Member State representatives, non-governmental stakeholders from advocacy groups and care organisations, as well as mental health care providers, professionals, and service users. The purpose of the Forum was to discuss the implementation of policy recommendations of the Joint Action European Framework for Action on Mental Health and Well-being and the outcomes of activities related to the work of the EU Compass during 2016-2017.



# SOCIETAL IMPACT OF PAIN

## SIP Symposium 2017 - Malta



The 7<sup>th</sup> symposium of the “Societal Impact of Pain” (SIP 2017) from June 7-9 in Valletta, Malta. SIP 2017 took place under the auspices of the 2017 Maltese Presidency of the Council of the EU with the title “Structured Cooperation between Health Care Systems tackling the societal impact of pain!” The symposium brought together about 300 international experts in the field of pain care, along with patient representatives, policy makers and other stakeholders in the field of pain policy and representing more than 200 international and national organisations.

Clear policy recommendations were formulated to change pain care in the European Union for the better and alleviate the effect of pain on society. Four working groups at SIP 2017 developed individual suggestions targeting the issues discussed:

1. Establish an EU platform on the societal impact of pain
2. Develop instruments to assess the societal impact of pain
3. Initiate policies addressing the impact of pain on employment
4. Prioritise pain within education for health care professionals, patients and the general public
5. Increase investment in research on the Societal Impact of Pain

As a major highlight at SIP 2017 - Martin Seychell, Deputy Director General in the European Commission responsible for Health and Food Safety, announced in his speech that the European Commission is following SIP's lead and has launched the “Expert Group on Social Impact of Pain” in the framework of the EU Health Policy Platform, to build a bridge between health systems and policy makers on the topic. Ultimately, the expert group that is to be composed will be an instrument that enhances best practice sharing across EU member states, in coordination with the Commission. Once fully functioning, public health groups in all areas, employers' organizations, insurers, economists and even digital stakeholders are expected to be involved. This is a huge step forward for our efforts and for patients throughout Europe.

Further, it has been a great achievement that under the leadership of the Maltese Presidency, EU Health Ministers have agreed that it is time to evaluate access to treatment for patients with chronic pain. This is a substantial step for pain patients throughout the EU, and will hopefully be carried forward as part of the Council of the European Union's continued focus on effective, accessible and resilient healthcare systems. The Societal Impact of Pain (SIP) platform is committed to ensure that these words are transformed into actions.



## SOCIETAL IMPACT OF PAIN

The scientific framework of the SIP symposium and platform is under the responsibility of the European Pain Federation EFIC®. Cooperation partners for SIP 2017 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The SIP 2017 symposium has been co-hosted by the Malta Health Network and the No Pain Foundation. The pharmaceutical company Grünenthal GmbH has been responsible for funding and non-financial support (e.g. logistical support).

Until now the objectives of the SIP platform have been endorsed by an impressive number of more than 300 pain advocacy and scientific organisations and that number is still increasing. This underlines the increasing awareness on the Societal Impact of Pain Initiative and is a great chance to collaborate together in a structured way involving all the different stakeholder groups.

In the coming months the partners of the SIP platform will continue to raise the SIP 2017 recommendations with policy makers and influential stakeholder. Further the "Expert Group on Social Impact of Pain" of the EU Health Policy Platform will be established to make this initiative a great success.



# MEDIA REPORT



## Access to brain disorder treatment worsening in EU

Written by Martin Banks on 26 June 2017 in News

The EU spends just over €3 a year per patient on research into brain disorders, while levels of access to treatment in many member states are worsening, a medical conference organised by the European Brain Council (EBC) heard.



The EU spends just over €3 a year per patient on research into brain disorders | Photo credit: Fotolia

The conference was given the findings of a new report, 'The value of treatment for brain disorders' (VoT), which highlights the need for more investment into research on neurological and mental diseases and the wide disparities between and within countries relating to treatments, detection and intervention.

The report aims to raise awareness of the 'treatment gap' and the need for more investment in research.

It shows, for example, that up to 70 per cent of people with epilepsy could become seizure-free with the best treatment currently available.

Parliament Magazine,  
"Access to brain disorder  
treatment worsening in EU",  
June 2017

**MONEY ON THE MIND:** The European Brain Council is out with an extensive [report](#) ahead of its conference today on the value of neurological care, and one of their key recommendations is more money for basic research to understand both the causes and progression of brain disorders, as well as R&D for treatments that could slow down or cure the conditions. Because there aren't cures for most neurological ailments, the report stresses improving prevention and early diagnosis.

"Up to eight out of ten people affected by brain disorders remain untreated, even though effective treatments exist in many cases," [said](#) EBC President David Nutt.

**POLITICO**

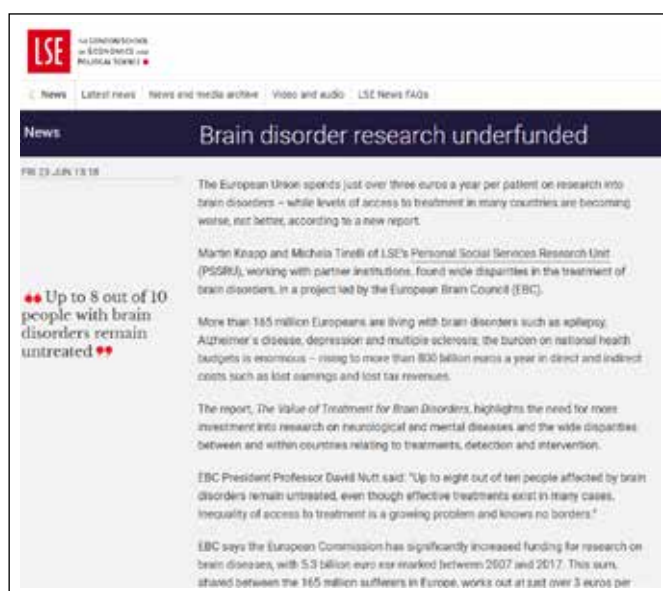
Politico Pro Morning Healthcare, "Money on the Mind", June 2017



# Reports



AGE Platform, "Raising awareness on dementia at a European Brain Council event"



Parliament Magazine, Politico, LSE News, AGE Platform & i-Prognosis covered the launch of the Value of Treatment project and closing conference, bringing to light the key findings of the report and the highlights of the conference held on 22 June.



## Recognising the challenges, adopting exceptional measures

year Bush Council

Frédéric Destrebecq and Stephanie Kramer highlight the challenges around workplace mental health following World Mental Health Day. In Europe alone, mental health conditions like depression place a heavy burden on society and workplaces, with an estimated 350 million working days lost due to mental health.



Open Access Government,  
“Workplace mental health: Healthy  
workforce, healthy society”,  
November 2017



Eurohealth, “The Value of Treatment:  
Early Intervention to Reduce the Burden of  
Brain Disorders”, December 2017



Parliament Magazine, “Bridging the gap”, December 2017

# FINANCIAL DATA

## Reports

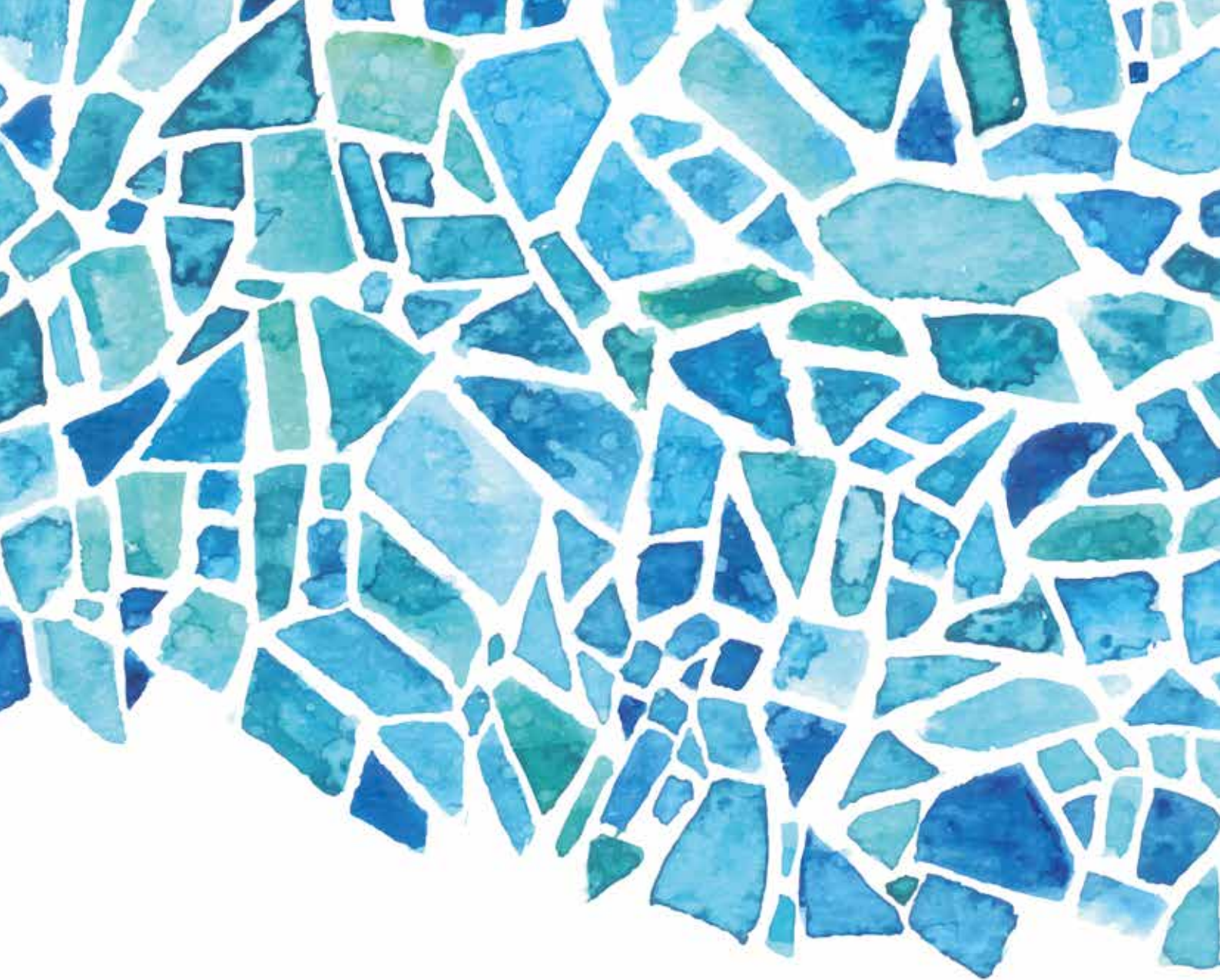
Membership Fees	40%
EBC projects (non EU-funded)	58%
EBC activities	2%



Team costs	27%
Meeting travel accomodation	13%
Services	41%
Advocacy and communication	17%
Other	2%







# **EBC EXECUTIVE & BRUSSELS OFFICE**



## EBC Executive



**Prof. Monica Di Luca**  
President



**Prof. Wolfgang Oertel**  
Vice-President



**Prof. Patrice Boyer**  
Vice-President



**Ms Joke Jarsmaa**  
Treasurer

## EBC Brussels Office



**Frederic Destrebecq**  
Executive Director



**Stephanie Kramer**  
Project Development  
Assistant / Communications  
& Advocacy Coordinator



**Giovanni Esposito**  
Research Project  
Manager



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



**Cécile Grebet**  
Finance & Administration  
Manager



**Marijn Scholte**  
Policy Intern / Policy Officer



**Tadeusz Hawrot**  
Senior Policy Officer



**Coumbis Hope Lowie**  
Office Manager

**Vania Putatti**  
Membership Coordinator

The progress achieved in 2017 was made possible by the great efforts of EBC's Executive as well as the team at our Brussels Office.

## Meetings Attended

- High-Level Policy Forum on people-centred care, Paris, OECD meeting, 16<sup>th</sup> January 2017
- ICT4Life project meeting: preparation EBC slides for presentation and meeting, 19<sup>th</sup> January 2017
- Suicide Prevention Working Group Meeting, Brussels, 9<sup>th</sup> February 2017
- EMSP EP Event: Can Real World Data Advance Equity of Health Care in Europe? 7<sup>th</sup> March 2017
- Not Myself Today Introduction Meeting with Symbio, Brussels, 13<sup>th</sup> March 2017
- Brain Awareness Week Lunch Dabte, Brussels, 14<sup>th</sup> March 2017
- Brain Awareness Week EPA Reception, Strasbourg FR, 15<sup>th</sup> March 2017
- Brain Awareness Week EDAB Speaker's Dinner, Strasbourg FR, 15<sup>th</sup> March 2017
- IMI meeting on Alzheimer's disease, 15<sup>th</sup> March 2017
- Brain Awareness Week EBC-FENS-EDAB Outreach Event, Strasbourg FR, 16<sup>th</sup> March 2017
- EURO CARE Event: 'Rehabilitation for Recovery and Reinsertion in the EU', Brussels, 20<sup>th</sup> March 2017
- EU OSHA Healthy Workplaces Campaign Partner Event, Brussels, 23<sup>rd</sup> March 2017
- EPA Congress, Florence IT, 1<sup>st</sup> - 4<sup>th</sup> April 2017
- Stakeholder Cooperation on Depression/Major Depressive Disorder meeting organized by Janssen, Florence IT, 2<sup>nd</sup> April & 10<sup>th</sup> November 2017
- Planning meeting with Shire for Transition of Care/ADHD expert group and policy paper, Brussels, 12<sup>th</sup> April 2017
- Eurocare Alcohol Labelling Coordination Meeting, Brussels, 26<sup>th</sup> April & 17<sup>th</sup> May & 18<sup>th</sup> September 2017
- High level debate – Tackling chronic diseases in Europe, Brussels, 26<sup>th</sup> April 2017
- FIPRA Value of Health meeting, 3<sup>rd</sup> May 2017
- PRIME 1st Anniversary Conference, European Medicines Agency (EMA), London UK, 18<sup>th</sup>-19<sup>th</sup> May 2017
- 'The Future of EU Drugs Policy. Can we do more to prevent drug-related deaths?', Brussels, 30<sup>th</sup> May 2017
- EURO CARE Seminar: 'Self-Regulation is No Regulation: The Case for Protecting Children from Alcohol Marketing', Brussels, 7<sup>th</sup> June 2017
- 'How to create an ecosystem which unlocks the full potential of health data?', Brussels, 7<sup>th</sup> June 2017
- Governmental experts group on mental health – European Commission - DG SANTE, Luxembourg, 8<sup>th</sup> June 2017
- EU Mental Health Compass Forum, Luxembourg, 8<sup>th</sup> - 9<sup>th</sup> June 2017
- FAIB General Assembly, Brussels, 14<sup>th</sup> June 2017
- EFPIA Annual Conference: Unlocking Tomorrow's Cures, Brussels, 14<sup>th</sup> June 2017
- Value of Treatment Celebration Dinner, Brussels, 21<sup>st</sup> June 2017
- Value of Treatment White Paper Launch & Closing Conference, Brussels, 22<sup>nd</sup> June 2017
- EAN Congress 2017, Amsterdam NL, 24<sup>th</sup>-27<sup>th</sup> June 2017
- Brain Tumors: Research and Societal Need, European Parliament, Brussels, 27<sup>th</sup> June 2017

## Meetings Attended

- ELSA Meeting, Brussels, 28<sup>th</sup> June 2017
- Lundbeck Global Patient Advocacy Summit, Copenhagen DK, 28<sup>th</sup> - 29<sup>th</sup> June 2017
- Estonian EC Presidency Joint Meeting of EU Chief Medical Officers, Chief Nursing Officers and Chief Dental Officers, "Stroke – Equal Access to Care and Quality of Care for All Patients", Tallin EST, 4<sup>th</sup> - 6<sup>th</sup> July 2017
- Meeting with EU Observer Magazine, Brussels, 10<sup>th</sup> July 2017
- ADHD Expert Policy Paper Workshop, Brussels, 11<sup>th</sup> July 2017
- Joint Meeting of the Interest Groups on Mental Health, Well-being and Brain Disorders and the Brain, Mind and Pain: 'The Value of Early Intervention' in the European Parliament, Brussels, 12<sup>th</sup> July 2017
- 3<sup>rd</sup> Academy of National Brain Councils, 12<sup>th</sup> - 13<sup>th</sup> July 2017
- MSD meeting on Alzheimer's Disease and digital technology, London UK, 14<sup>th</sup> July 2017
- ECNP Congress, Paris FR, 2<sup>nd</sup> - 5<sup>th</sup> September 2017
- 'Make Health Your Business' event, Brussels, 7<sup>th</sup> September 2017
- European Medicines Agency, Awareness Event, London UK, 18<sup>th</sup> - 19<sup>th</sup> September 2017
- EU Design Days 2017, Brussels, 19<sup>th</sup> - 20<sup>th</sup> September 2017
- 'Research & Innovation for Europe. What after 2020?', Brussels, 27<sup>th</sup> September 2017
- FAIB lunch-debate on GDPR, Brussels, 28<sup>th</sup> September 2017
- Digital Open Science: Solving the Social and Sustainability Challenges of the 21<sup>st</sup> Century, Brussels, 28<sup>th</sup> September
- Alzheimer Europe Conference, Berlin DE, 2<sup>nd</sup> - 4<sup>th</sup> October 2017
- 1<sup>st</sup> Hearing of the Expert Panel on Effective Ways of Investing in Health, Brussels, 3<sup>rd</sup> October 2017
- 4<sup>th</sup> Steering Committee Meeting of the "Societal Impact of Pain", Brussels, 4<sup>th</sup> October
- European Parliament event: 'Geography matters: Inequalities in Access to Stroke Care and Innovation in Europe', Brussels, 10<sup>th</sup> October 2017
- STOA Workshop: Therapies for the Future, Brussels, 11<sup>th</sup> October 2017
- Mental Health Europe Event: 'Mental health promotion in the workplace', European Parliament, Brussels, 11<sup>th</sup> October 2017
- EXPH Hearing to discuss "Benchmarking Access to Healthcare in the EU", Brussels 11<sup>th</sup> October 2017
- Estonian EU Presidency High-level conference on e-health 'Health in the digital society. The digital society for health', Tallinn EST, 16<sup>th</sup> October 2017
- European Health Parliament - 1<sup>st</sup> Plenary, Brussels, 17<sup>th</sup> October & 5 December 2017
- IMI Stakeholder Forum, Brussels, 18<sup>th</sup> October 2017
- 3<sup>rd</sup> Hearing of the Expert Panel on Effective Ways of Investing in Health, Brussels, 25<sup>th</sup> October
- Launch of the Commissioned Issue on TBI for The Lancet Neurology, European Parliament, Brussels, 7<sup>th</sup> November 2017
- UIA Association Round Table Europe 2017, Brussels, 10<sup>th</sup> November 2017
- The Value of Health Meeting, FIPRA, Brussels, 16<sup>th</sup> November 2017

## Meetings Attended

- EP Interest Group on Mental Health: 'Bridging the Gap' Expert Policy Paper Launch at the European Parliament, Brussels, 21<sup>st</sup> November 2017
- EBC eHealth Event in the European Parliament: 'Brain Health: The digital future is on its way', Brussels, 22<sup>nd</sup> November 2017
- European Alliance for Personalised Medicine Congress – Personalising Your Health: A Global Imperative!, Belfast UK, 27<sup>th</sup> - 30<sup>th</sup> November 2017
- Training session at POLITICO Europe: 'How to engage with media and maximize social media & how to effectively engage with EU', Brussels, 29<sup>th</sup> November 2017
- European Headache Federation Conference, Rome IT, 30<sup>th</sup> November - 3<sup>rd</sup> December 2017
- AETIONOMY General Assembly Meeting, Basel CH, 30<sup>th</sup> November & 1<sup>st</sup> December
- Value of Treatment Headache Working Group Meeting, EHF Conference, Rome IT, 3<sup>rd</sup> December 2017
- Meeting with the Women's Brain Project team, Brussels, 4<sup>th</sup> December 2017
- 'How can the EU incentivize access to affordable medicines for all? Building on the recommendations of the UN High-Level Panel on Access to Medicines', Brussels, 5<sup>th</sup> December
- 'Engaging Patients in the Digital Revolution: A Call to Build Smarter and Safer Healthcare Systems', Brussels, 5<sup>th</sup> December
- 'Embedding digital into societal challenges', Brussels, 7<sup>th</sup> December 2017
- The Potential Impact of Brexit on Health in Britain and Europe, Brussels, 7<sup>th</sup> December 2017
- Info DAY H2020, Brussels, 8<sup>th</sup> December 2017
- Excellence in Pediatrics Conference, Vienna AT, 8<sup>th</sup> - 9<sup>th</sup> December 2017
- GOLUP Round Table "L'uso dei medicinali off-label in Italia", Rome IT, 13<sup>th</sup> December 2017
- FAIB lunch-debate Year 2017 in review, Brussels, 15<sup>th</sup> December 2017
- 'Update: research and innovation priorities of the Bulgarian EU-Presidency', Brussels, 15<sup>th</sup> December 2017

## Annex of Speakers at EBC Board Meetings

### BM1: 8-9<sup>TH</sup> FEBRUARY, 2017

#### Board Dinner

Dr Philippe Cupers: Deputy Head of Unit for Health Strategy at DG Research and Innovation of the European Commission

**Topic:** Innovation in health

Mr Marc Lange, Secretary General, EHTEL European Health Telematics Association

**Topic:** EHTEL Introduction & innovations in eHealth



## Annex of Speakers at EBC Board Meetings

Prof Andrea Fiorillo, EPA Board member

**Topic:** EPA work in eMentalHealth

### Board Meeting

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

**Topic:** Update on activities of DG Research and Innovation & thoughts on eHealth

### BM2: 21 JUNE 2017

### General Assembly

Dr Nicola Specchio – Paediatric Hospital “Bambino Gesù”, Rome (Italy)

**Topic:** Challenges in Neuropediatric and Primary & Secondary Prevention

Prof. Celso Arango – President of the European College of Neuropsychopharmacology (ECNP)

**Topic:** Primary and Secondary prevention in Psychiatry - A focus on children and adolescents

### BM3: 13<sup>TH</sup> – 14<sup>TH</sup> SEPTEMBER 2017

### Board Dinner

Dr. Robert Jakob, Team Leader Classifications and Terminologies (ICD, ICF, ICHI), World Health Organisation

**Topic:** The 11<sup>th</sup> Revision of the International Classification of Disease (WHO ICD – 11): State of Play and Challenges – Implications for Brain Disorders

### BM4: 22<sup>ND</sup>-23<sup>RD</sup> NOVEMBER 2017

### Board Meeting

Kim Krogsgaard, Managing Director, Lundbeck Foundation

**Topic:** The Brain Prize: “The world’s most valuable prize for brain research”

Catherine Hartmann – Vice-President, European Public Health Alliance

**Topic:** Challenges to research on CNS disorders

Chris Nas - Senior Policy Advisor, Department Trimbos International

**Topic:** Introduction of the Trimbos Institute



# CREDITS

This report was compiled  
by the team of EBC's Brussels Office.



Graphic design by Cookdesign srl

This report has been designed in line  
with best practice guidelines of visual accessibility.

We welcome feedback and suggestions  
for maximising the readability of our publications.

Please email your comments to  
**[info@braincouncil.eu](mailto:info@braincouncil.eu)**



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