



IMPROVING
BRAIN KNOWLEDGE
AND ADVOCACY

EBC ANNUAL REPORT

2016

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INTRODUCTION

By David Nutt & Frédéric Destrebecq

A stylized, cursive signature of Prof. David Nutt in black ink.

Prof. David Nutt
President

A stylized, cursive signature of Frédéric Destrebecq in black ink.

Frédéric Destrebecq
Executive Director

Dear Colleague,

The European Brain Council is pleased to present to you the Annual Report for the year 2016.

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 delivers on its mission and vision by working on substantive innovations itself, 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.

2016 was a remarkable year for EBC, thanks to the development of an increasing number of activities including advocacy and networking initiatives, awareness raising campaigns and projects.

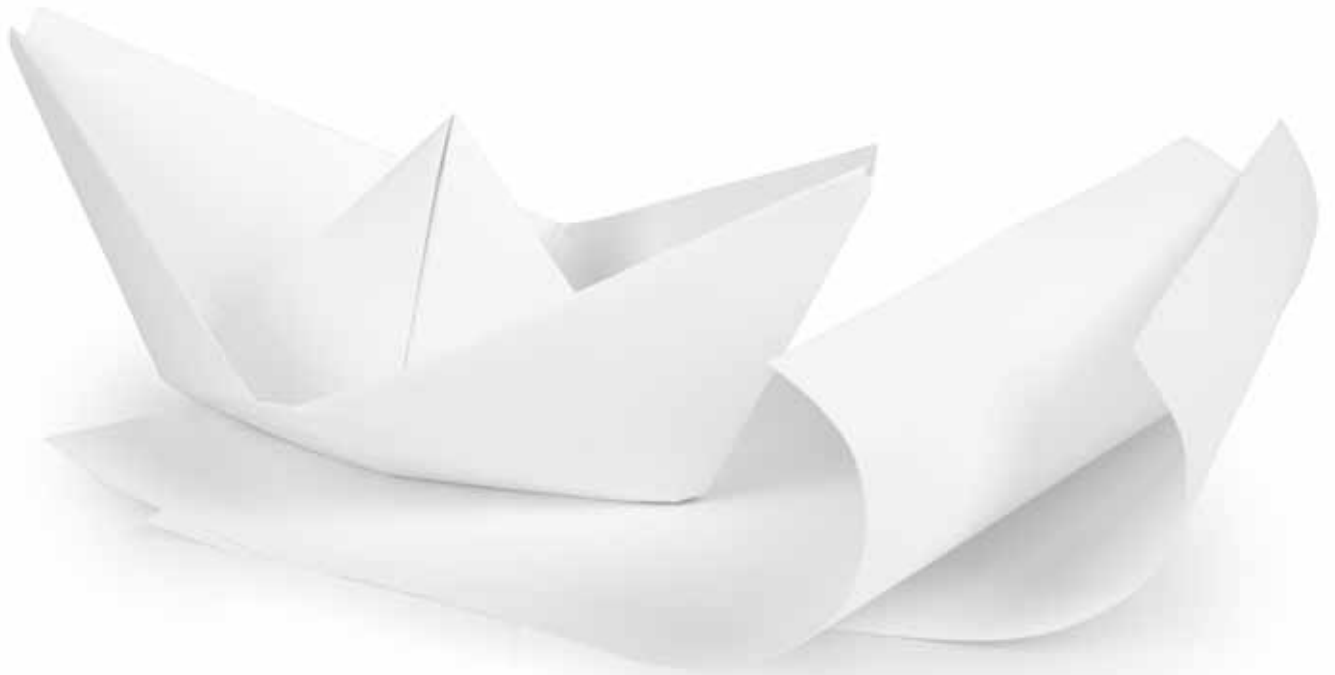
EBC was directly involved in a number of public and closed events that contributed to enhancing its presence and recognition within the EU institutions, the field of health policy, the general public, the neurological and psychiatric community, and other stakeholders. EBC's action was indeed acknowledged in the Innovation Report of the European Commission (EC) and EBC was invited to speak by the Directorate General (DG) for Health and Food Safety, the DG for Employment, Social Affairs & Inclusion and European Council Research working party, to name just a few. By strengthening its outreach within the European Parliament, EBC was able to collaborate and work with a number of Members of the European Parliament (MEPs) active on issues relating to the brain through opportunities to contribute to the work of the ENVI Committee Workshop "Living with a Brain disorder: taking control of your life", and an invitation from the Science and Technology Options Assessment (STOA) to lead the research project and related study on "Technological Innovation Strategies in Substance Use Disorders".

In 2016, EBC dedicated particular attention to expanding into the field of mental health. While EBC continues to be involved in EU institution initiatives and committees like the Group of governmental experts on mental health and wellbeing, the EU Compass for Action on Mental Health and Well-Being, and OSHA's "Healthy Workplaces for all Ages" campaign, 2016 was also the first year where EBC decided to take on an initiative of its own. EBC is strongly convinced that mental health and well-being of the workforce is a key resource for productivity and innovation in the EU, and thus launched its partnership with Canadian mental health at work campaign, Not Myself Today.

The launch of Phase 2 of EBC's research project the Value of Treatment for Brain Disorders in Europe represented an exceptional achievement for our organisation, and dominated a lot of EBC's activities in 2016. The project, examining the socio-economic impact of treatment and non-treatment of various brain disorders, continues to bring out incredible data thanks to the close collaboration with EBC's members and partners. Throughout the year, the working groups had the opportunity to meet in multiple occasions in order to develop a socioeconomic impact evaluation in parallel with the patient journey of nine different case studies focussing on a series of many mental and neurological disorders. The project's policy white paper will be launched mid-2017.

Though 2016 can be seen as a highly successful year for EBC and we experienced an exceptional improvement in terms of activities and reputation at the EU level we continue to look forward to ensuring that and striving for the interests of our members and partners are defended, promoted and recognised by the European institutions' level to endorse the long-term development of brain research and the improvement of the lives of those living with brain disorders in the EU.

EBC MISSION & VISION



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

EBC HIGHLIGHTS



EBC HIGHLIGHTS

Consensus Statement – The need to expand Brain Research in Europe

The European Brain Council (EBC) launched on 18th March 2016 the Consensus Statement: *"The need to expand Brain Research: the need to expand brain research in Europe"*.

In promoting brain health in Europe, EBC recognizes the vital need to create a body of evidence supporting our call to give the brain a higher priority as well as to provide policy makers with the state-of-the-art knowledge concerning key needs in the field of brain research. EBC's Consensus paper is answering to this.

The document was prepared by EBC, together with its Members and partners, and in collaboration with over one hundred European scientists and patient representatives. It not only presents proposals for future research programmes but also describes the needs and achievements of research in Europe.

On 3rd July 2016, EBC and FENS organized a special interest event dedicated to the Consensus Statement, which was widely promoted by Prof. Monica di Luca, FENS president, at the event as well as during the opening ceremony of the FENS Annual Forum.

In addition, EBC had a unique opportunity to present on the 23rd September its activities and priorities to senior representatives from research ministries from all EU Member States as well as research attaches from 28 EU Member States. This opportunity was provided by Slovakian Presidency of the EU that invited EBC to present at the meeting.



EU Council Research Working Party, Brussels, 23rd September 2016

Call to action for the adoption of the National Brain Plans

In November 2015, the European Brain Council (EBC) launched a Call to Action, calling on the European Commission to come forward with a European strategy to tackle brain disorders, and on European countries to implement public health programmes addressing brain health.

This continued to be an important priority for EBC in 2016 and had been particularly highlighted during the National Brain Councils (NBCs) Academy in Brussels in May 2016. Two external speakers Jelka Zaletel and Tit Albrecht spoke about their experience with EU Joint Actions on chronic diseases (CHRODIS) and EU Partnership for Action Against Cancer. Both initiatives resulted in the creation of National Plans for Diabetes and Cancer through EU member states.

A NBCs task force had been subsequently formed to foster the creation of NBPs with the participation of Belgium, Bulgaria, France, the Netherlands, Norway, Poland, Spain, Serbia and Slovenia. The taskforce held its first teleconference on October 2016 in order to exchange current experience and discuss the way forward.

EBC continued to be involved in the CHRODIS developments and to this end EBC representatives attended the project's General Assembly in Madrid on 4th February and the EC Conference "Towards better prevention and management of chronic diseases" on 21st April. Last but not least, EBC gave a presentation at the CHRODIS meeting in Rome on 20th October.



Call to action for the adoption of the National Brain Plans

Joint Actions are a funding instrument under the third EU Health Programme 2014-2020. They are designed and financed by Member State authorities and the EU to address specific priorities under the EU Health Programme. They have a clear EU added value and are co-financed either by competent authorities that are responsible for health in the Member States (e.g. Health Ministries) or in the third countries participating in the Programme, or by public sector bodies and non-governmental bodies mandated by those competent authorities. Joint Actions involve on average 25 partners, depending on the scope of the action. With 71 partners, JA-CHRODIS is the largest Joint Action co-financed under the EU Public Health Programme to date. Reducing the burden of chronic diseases like diabetes, cardiovascular disease, cancer and mental disorders is a priority for EU Member States and at the EU Policy level, since they affect 8 out of 10 people aged over 65 in Europe. There is great potential to reduce the burden of chronic disease by making better use of the available knowledge. JA-CHRODIS has been designed to exploit this potential.

In the framework of developing a Polish Brain Plan, EBC was presenting together with the Polish Brain Council at the Brain Health Discussion Panel during **the 26th Economic Forum** in Krynica, Poland. The forum is one the most important get-togethers of its kind in Central and Eastern Europe and has seen the participation of Polish and foreign high officials, EU Commissioners, CEO businesses and scientists.



Economic Forum, Brain Health Panel, Krynica, 6th-8th September 2016

Living with a Brain disorder: taking control of your life EP ENVI Committee workshop

On 12 October 2016 EBC was invited to present the report *Living with a Neurological Brain Disorder: Taking Control of Your Life*.

The Report summarises the presentations and discussions of the workshop on neurological brain disorders. The aim of the workshop was to provide background information on the main characteristics of neurological brain disorders, as well as to identify new strategies and innovative tools to better support the prevention and treatment of these diseases. The latest data, trends, and challenges in the field of neurological brain disorders were highlighted during the first part of the workshop. Moreover, speakers illustrated how mHealth tools can better support treatment for patients affected by brain disorders.

Successful examples of mHealth tools, such as the app “MyDystonia”, were also presented. The second part of the workshop focused on the potential offered by mHealth for patients with neurological brain disorders. Relevant initiatives carried out by the European Commission were presented, and the importance of involving patients in the designing of new mHealth tools for the treatment of brain disorders was also discussed. This workshop and the respective document were prepared by the Policy Department A at the request of the Committee on Environment, Public Health and Food Safety.



European Parliament, Committee on Environment, Public Health and Food Safety - Members

Opportunity now: Europe's mission to innovate European Commission's Report

The **Innovation Report**, a review conducted by **Robert Madelin** on innovation in Europe, has been published on 5th July 2016. The paper has been produced by the **European Political Strategy Centre (EPSC)**, the European Commission's new think tank, where Madelin, former director general at DG Connect, acted as an adviser on innovation.

In its first two sections, the report acknowledges the difficulties and complexities of innovation, and calls for "more open collaboration, both globally and between citizens, governments and inventors at home".

Open structures involving citizens and aimed at prioritizing innovation could be set up within each political institution, at the national as well as the European level.

The third part, titled "**People, Place and Process**" claims that sustained innovation success requires not only to face the science and funding challenges, but also a parallel action in three fields: human capital, geography and public institutions. Interestingly, when addressing people's health, the report calls for a **stronger support of mental health** and acknowledges the action of the European Brain Council. It reads: "In cognitive and emotional wellness, **the European Brain Council's Year of the Brain remade the positive case for investing in brain well-being**. This is a goal that covers the full gamut of innovation, from genomics and high-throughput neurological databases to web-based virtual reality support for psychotherapy. Yet these issues of stigma are woefully underfunded. Physically, too, we can

feel proud about average overall longevity, but we should not ignore the stagnation and in many places marginal decline in the share of our lives spent in good health (Healthy Life Years). This state of affairs implies both avoidable illness for fellow-citizens and a workforce shrunken by impaired physical mobility and an unduly early end of productive activity." However, innovative answers to the health sectors can come from eHealth and mHealth. The EIT (European Institute of Technology) can have a role in coordinating the Health community and creating a collaborative approach to health innovation, that links all the existing opportunities.

Concerning education, the paper argues that **universities** need a lateral and disruptive transformation in order to become "entrepreneurial ecosystems", places that are "good for society and innovation as well as good at research and teaching". About money for research, Madelin suggests revising the procedures currently in place for researchers applying for **European funding**, as "the conditions for EU funding continue to deter some excellent teams in some excellent institutions from even bothering to read the H2020 calls". Innovators should also be granted a wider access to investment finance.

Finally, the report calls for action now and indicates the preferred path in this direction. The **European Commission**, and in particular its President, Jean-Claude Juncker, will have the final decision on whether to act on the report's suggestions.

PROJECTS & INITIATIVES



PROJECTS & INITIATIVES

Value of Treatment for Brain Disorders in Europe - Phase 2 Launch



Value of treatment is a 2-year research project that aims to address the treatment gap of brain disorders in Europe and provide solutions to improve the quality of care. The treatment gap refers to the number of people with an illness, disease or disorder who need treatment but do not get it. **Out of 10 persons affected by brain disorders, up to 8 do not have access to adequate treatment, even though effective treatments exist in some cases.** VoT assesses the full scale of unmet healthcare needs in Europe regarding schizophrenia, Alzheimer's disease (AD), headache, stroke, Parkinson's disease, epilepsy, multiple sclerosis (MS), restless legs syndrome (RSL) and normal pressure hydrocephalus (NPH).

Brain Disorders, including both mental and nervous system disorders, represent an enormous burden on individuals and

societies. The broader impact of brain disorders, which in the future is likely to be even greater, is threatening the quality of life of millions of European citizens. In this context, the "VoT" project aims to provide policy recommendations for delivering optimal health care services.

The EBC held a kick-off event on 27th January 2016 to inaugurate the 2nd phase followed by the 1st joint working group meeting which officially opened the work of the case studies which ran throughout 2016. The meeting brought together key stakeholders and experts working with the brain disorders that are central in the VoT study. **David Nutt, President of EBC, explained that the value of treatment project will provide "an in-depth analysis on why we are not optimizing treatment. This project will explore the effectiveness and efficiency of coordinated healthcare models."** Prof. Nutt also emphasized the need for increased funding in brain research.



3rd VoT Roundtable, Brussels, 8th January 2016

PROJECTS & INITIATIVES

Value of Treatment for Brain Disorders in Europe - Phase 2 Launch

Each working group, composed of a multi-stakeholder team of clinicians, patient groups and industry representatives, used a combination of qualitative and quantitative approaches to identify the major treatment gaps along the clinical pathway and propose solutions to address them while highlighting their socio-economic impact. Specific smaller working group meetings were organized throughout 2016.

The kick-off meeting in January was followed by the presentation of the first discussion paper "Exploring the potential for a holistic care model for brain disorders to close the treatment gap in Europe: development of a workable care model and case studies analysis". The paper aims to set the scene and explore challenges concerning the 9 brain disorders that are central to the VoT study as well as examining options for optimal patient-centrated care strategies.

On 28th September 2016 the EBC held the 2nd joint working group meeting. On that occasion, each working group presented the preliminary results of their analyses, thereby providing an overview of what was accomplished thus far.

The EBC aims to share the conclusions of the Value of Treatment project in a White Paper in June 2017, followed by a launch in the European Parliament in July. This publication will include the results of 9 case studies on mental and neurological disorders. Thereby the project will reach out to those suffering from brain disorders by providing policy recommendations for realizing cost-effective and good quality care.

PROJECTS & INITIATIVES

Value of Treatment for Brain Disorders in Europe - Phase 2 Launch



PROJECTS & INITIATIVES

Not Myself Today – Europe

Healthy workforce is a cross-cutting issue that can be identified in all the three pillars on which EBC is basing its mission – i) drive education and awareness, ii) promote prevention and treatment, and iii) stimulate innovation.

EBC is strongly convinced that mental health and well-being of the workforce is a key resource for productivity and innovation in the European Union. EBC has been involved in a number of initiatives to address healthy workforce in the past, and in 2016 continued to build on its previous experience in the field of promoting healthy workplace and will begin the development and formation of a dedicated campaign on mental health in the workplace.

Mental health is everyone's business. We're all affected by it. In the workplace, the cost of doing nothing is staggering, both personally and economically.

Not Myself Today was introduced to workplaces in Canada in 2013 by Partners for Mental Health Canada to encourage employers and employees to transform mental health at work, and is now being piloted by EBC in Europe. In the past three years, the campaign has informed, engaged, recruited, mobilized and partnered with people and organisations to successful and meaningful change in the improvement of mental health. Through this initiative, European companies and organizations will receive comprehensive resources and tools to organize events and activities that engage employees and aims to reduce stigma and create cultures of acceptance and support for mental health and for those who are facing mental illness.

On 16th June 2016, EBC and Partners for Mental Health Canada officially signed a memorandum of understanding to begin the partnership and held the first advisory committee meeting.



Signing of the Memorandum of Understanding with Partners for Mental Health Canada, Brussels, 16th June 2016



First Not Myself Today EU Advisory Committee Meeting, Brussels, 16th June 2016

PROJECTS & INITIATIVES

Not Myself Today – Europe

This meeting involved various experts from the field of mental health and employment, bringing together psychiatrists, union representatives, employment experts and mental health organisations.

The campaign was introduced in depth, and the toolkit was broken down and discussed, with all sharing their views on what they believed was fit for purpose or needed adaptation in order to propose the initiative in Europe.

Throughout the rest of the year, EBC was invited to participate in a series of meetings and events on mental health and specifically mental health in the workplace across Europe. The initiative has been presented at the Meeting of Governmental Experts on Mental Health and Wellbeing, Oct. 2016, at DG SANTE, Luxembourg; to DG Employment and DG Human Resources; the European Agency for Safety and Health at Work (OSHA);

Lundbeck's Global Patient Advocacy Summit, June 2016, Copenhagen; and potential partners within the private sector and EBC member organisations. Furthermore, EBC and Not Myself Today EU have taken part in the ILO Mental Health at Work Expert Meeting, Geneva; EU Compass Forum on Mental Health and Wellbeing, Luxembourg; The European Business Leadership Forum, London; and meetings of the Expert Platform on Mental Health, Brussels.



NOT
myself
TODAY®



DG SANTE's Governmental Expert Group on Mental Health, Luxembourg, 5th October 2016



EBC's Strategic Workshop, Brussels, 29th September 2016

PROJECTS & INITIATIVES

EU-Funded Projects

NERRI

In 2016 EBC completed a three years long project NERRI – Neuro-enhancement Responsible Research and Innovation (RRI). Supported by the European Commission, it aimed to contribute to the introduction of RRI in neuro-enhancement (NE) and to shape a normative framework underpinning the governance of NE technologies. EBC was a full partner, providing strategic and operational advice on all aspects of the work including civil society engagement, the mobilisation of scientists and commercial sector companies and patient groups, communication and dissemination.

Throughout the course of the project, EBC has organized three mutual learning exercises with representatives of EBC Board, the National Brain Councils and as well as the patient groups during the congress of the European Academy of Neurology.

In order to disseminate the final project outcomes among the policy makers, EBC has cooperated with the Science and Technology Options Assessment (STOA) Panel in organizing a STOA Working Breakfast: A European Approach to Human Enhancement on 16th February on the premises of the European Parliament.



NERRI working Breakfast, Brussels, 16th February 2016

AETIONOMY & MARATONE

EBC continued with its involvement in Innovative Medicines Initiative funded project AETIONOMY tackling the challenge of classifying neuro-degenerative diseases as well as Framework Programme 7 funded project MARATONE, a Marie Curie Skłodowska Initial Training Network project that addresses the need for high level training and career pathways in mental health. On 19th-20th September EBC representatives attended the MARATONE conference in Madrid and on 10th October EBC contributed to the works of the Legal and Ethical Advisory Board during the project's meeting in Barcelona.



ADVOCACY & OUTREACH

ADVOCACY & OUTREACH

Visibility

In 2016 EBC had been building on the previous success demonstrated by a sharp increase of funding spent on brain research under EU funding schemes. EBC continued offering information and advice to European Institutions and other bodies in order to help ensure that policies promoting brain health are in line with the perspectives of scientists, patients and industry.

At the same time, EBC had significantly strengthened its role as a one-stop-shop for key stakeholders and this has been recognized on a number of occasions from organizations such as European Parliament, European Commission and European Union Member States.

A high number of meetings took place with Members of the European Parliament, representatives of the European Commission and other international organisations such as World Health Organization (WHO) and the Economic Organisation for Economic Co-operation and Development (OECD).

EBC had also been strengthening its influence at the level of the EU Council by getting engaged with EU Permanent Representations from Bulgaria, Malta, Poland and Slovakia.

This had been further pursued by EBC's involvement in the EU Presidencies and to this end EBC took part in a number of relevant meetings including the Netherlands Presidency event on 9-10th May: Living well with(out) dementia, as well as the Slovakia Presidency meeting: Alzheimer's disease – the epidemic of the third millennium, that took place on 29th November.

For a full list of meetings, please consult Annex 1



Dutch Presidency Conference, Amsterdam, 9th-10th May 2016

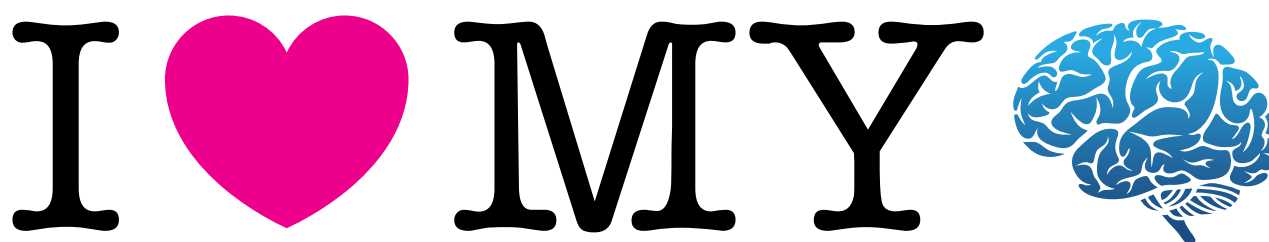
ADVOCACY & OUTREACH

#ILoveMy Brain

EBC's campaign ILoveMyBrain was officially kicked off on the occasion of a Policy Workshop dedicated to AF-Related Stroke that was organised on 25th January 2017.

Started by EBC, but encouraged to be used by anyone wishing to raise awareness on brain-related matters, **the #ILoveMyBrain logo is a communication tool aiming to promote and connect all the work being done to support brain health and prevent and treat brain disorders in Europe.**

The aim of working under the "I love my brain" logo is to bring the "brain community" together. Different organisations, researchers, patients and carriers all work and focus on different conditions, but EBC believes that by bringing together the very diverse activities which cover various brain disorders, everybody can benefit. Using a common logo, which is repeatedly seen in public and in the media, will help to gain more attention for brain disorders from EU policy makers, and ensure that more resources are channeled towards research on the brain and for patients of brain disorders.



ADVOCACY & OUTREACH

#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, EBC is getting involved with different Brussels events. This year, EBC's team took part in the Brussels 20km run on 29th May and the Acerta Marathon Team Relay (a series of relay runs adding up to the marathon distance of 42km) on 15th October.



20 Km Run, Brussels, 29th May 2016



Acerta Marathon Team Relay, Brussels, 15th October 2016



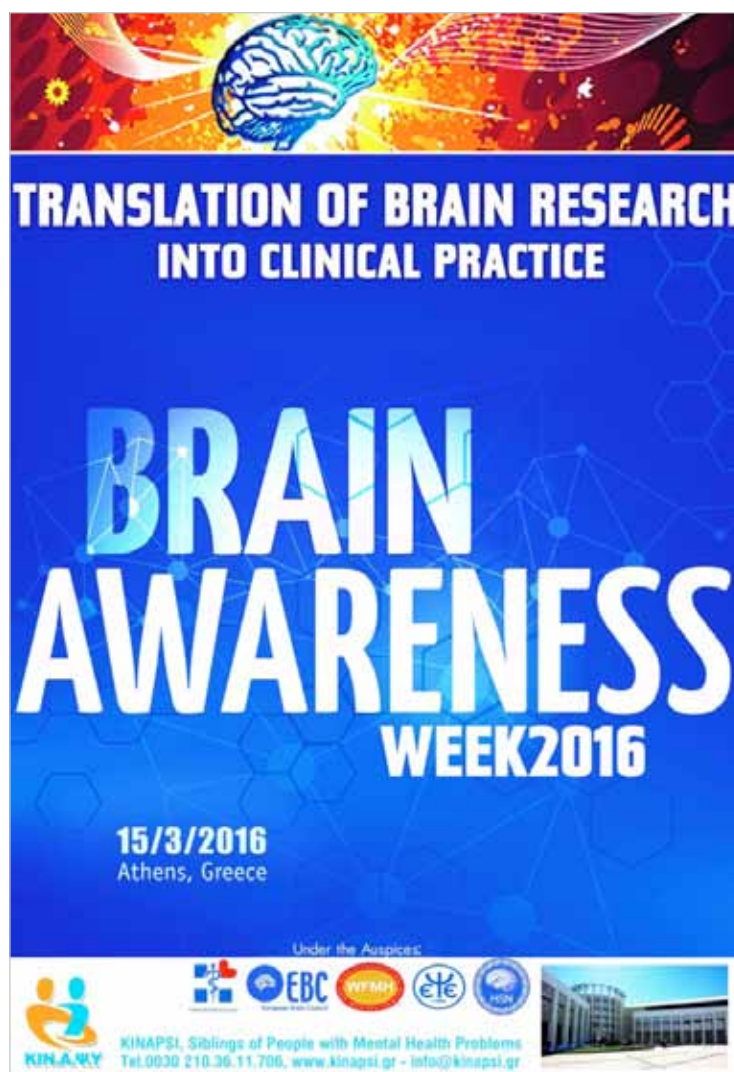
ADVOCACY & OUTREACH

Brain Awareness Week 2016

On an annual basis the brain research community celebrates the Brain Awareness Week (BAW) - a global campaign to increase public awareness of the progress and benefits of brain research.

The EBC is joining the celebration via different means such as organizing/ taking part in relevant events and activities and coordinating initiatives with its members. In 2016 one of the examples included speaking at the BAW event in Athens entitled "Translation of Brain Research into Clinical Practice". The event was co-organised by representatives of Greek academia together with the Kinapsi organisation, a charity for the siblings of people living with mental illness in Greece and coincided with a meeting of a Hellenic Action Group for the Brain.

EBC also liaised with Profesor Jerzy Buzek, EBC Honorary Member, Member of the European Parliament and Chair of the Research Committee which resulted in the publication of an article in the Parliament Magazine on the occasion of the BAW.



BAW Greece, Athens, 15th March 2016

BRAIN AWARENESS WEEK

European countries cannot tackle brain disorders alone

Millions of EU citizens are affected by brain disorders and member states will only be able to take on the challenge if they work together, writes **Jerzy Buzek**



Jerzy Buzek (EPP, PL)
is Chair of Parliament's
industry, research and
energy committee

The human brain is considered the most complex single organism in the universe. Not only can this 'super computer' generate theories on the origins of matter and life and develop devices to access the outer edges of our universe, it also steers our feeling, emotions and personalities.

This is what we are reminded of as we celebrate the annual "Brain Awareness Week" from 14 to 20 March 2016. This global campaign contributes to increasing public awareness on the progress and benefits of brain research. I am personally convinced that brain research has never been more important. One in three Europeans – 165 million people – is likely to be affected by a brain disorder, spanning more than 200 conditions from neurodegenerative diseases such as Alzheimer's and Parkinson's diseases, to mental health disorders such as depression and schizophrenia. Treating these conditions costs the EU €798bn each year, an amount that will increase significantly in future. And yet many of the most common and severe brain disorders are either preventable or can be remedied with inexpensive therapies. For example,

the World Bank ranks treatment for epilepsy and secondary stroke prevention as examples of 'best buys' in global health.

Reducing disease and disability linked to brain disorders is undoubtedly one of the greatest scientific challenges for the decades to come. Improving our knowledge of the brain will have long-term benefits. It could play a greater role in driving innovation in Europe; only with healthy brains will we be able to tackle the most pressing challenges the EU currently faces. As Parliament's rapporteur on FP7, I encouraged the Commission to focus on the brain. Much to my satisfaction, they have listened to my recommendations.

More research in this field is crucial, but we cannot overlook other relevant issues. We need to improve awareness, remove the stigma or myths associated with brain disorders. We must highlight the need for the right infrastructure and policies, develop the right regulatory environment, encourage innovation, facilitate the absorption and integrate research

results into policy and good practice, as well as greater consideration

for patients' needs.

This requires greater collaboration among the scientific community, research funding agencies, governments, academic institutions, multilateral organisations, advocacy organisations and health providers. No EU country alone has the expertise or the resources to tackle these issues alone. Real progress can only be made by working together. Therefore, I welcome more integrated, innovative, and coordinated national efforts. This should be strengthened by EU-led initiatives to assist countries in devising, adopting and implementing National Brain Plans. These multi-sectoral efforts should be directed at promoting good practices in targeted prevention, health promotion, timely diagnosis, post-diagnostic support and therapy, research, training and further education of health professionals. They should also improve the quality of epidemiological data on brain disorders.

Similar successful initiatives show that even if health remains a national responsibility, joint European action can create considerable added value by confronting the major challenges in brain health in a more efficient way. This will help avoid ineffective action or duplication of roles as well as encouraging better use of available resources. ★

"One in three Europeans – 165 million people – is likely to be affected by a brain disorder"



COLLABORATION



COLLABORATION

Together Under the Umbrella Campaign

“Together Under the Umbrella” is an innovative European campaign launched on 16th March 2016 at the European Parliament on the occasion of the Brain Awareness Week 2016. The initiative aims at educating society on the range of brain disorders and the number of people affected and to raise awareness on the impact and prevalence of these conditions.

The Campaign provides a platform for people with neurological disorders to share their experiences and stories and thereby build a greater understanding of these conditions among the wider public. It reminds people that 1 in 3 Europeans may suffer from a brain disorder in their lifetime.

“Together Under the Umbrella”, initiated by EFNA, the European Federation of Neurological Associations is linked to EBC’s Call for Action and represents a significant example of cooperation between EBC and its members.

The Campaign has been highly welcomed by 40 Members of the European Parliament, the Belgian Health Minister and well-respected leaders in the field – such as Prof. Richard Morris OBE and Brain Prize winner – who were photographed ‘under the umbrella’. It is also supported by many other stakeholders, including the Gamian-Europe and the European Patient Forum.



Launch of the campaign in the European Parliament with MEP Marek Plura, Brussels, 16th March 2016

To build on the political support, EFNA is now asking people to post a picture of themselves under an umbrella on social media using the hashtag #UnderTheUmbrella and linking to the campaign’s online hub.



EBC under the umbrella with Xavier Prats-Monné, Director General in DG Santé, Brussels, Belgium, 25th-26th May 2017

COLLABORATION

Technological innovation strategies in substance use disorders - STOA Report

EBC has participated to the works of the Science and Technology Option Assessment (STOA) Panel, composed by 25 Members of the European Parliament who are nominated by nine permanent Committees of the Parliament: AGRI, CULT, EMPL, ENVI, IMCO, ITRE, JURI, LIBE and TRAN.

EBC has contributed to the publication of the study "Technological innovation strategies in substance use disorders" (2015-2016) through the involvement of high level experts in the field of addiction drawn within its network of professionals.

The study fulfilled its objective to assess the formulation of different policy options on how new technologies can support the control and cure of dependency. In this framework, EBC was in charge of drawing up part of the study, which includes the production of high-quality data collection through the conduction of a survey and semi-structured interviews among European experts in the field of addiction with the aim to highlight the current state and future trends of the clinical implementation of ICT-based interventions in the treatment of substance use disorders in Europe.

This was possible thanks to the important contribution of EBC's Members, the European Psychiatric Association, its Subsection on Addictive Behaviors and its Dutch, Italian and English National Psychiatric Associations/Societies as well as the European Academy of Neurology and its Sub-Specialty Panel of Neurotoxicology.

The results of the study were presented by the STOA Panel together with EBC on the 19th January 2017 in the European Parliament in Strasbourg. The event was warmly welcomed by the attendants, including professional associations, MEPs and other stakeholders.

Key speaker, Prof. Giuseppe Carrà, EPA member of the Section on Addictive Behaviours and Professor at the University Bicocca of Milan, presented the results of the EBC contribution to the study which stated the potential benefit of these technologies in the treatment of addictions identified the major barriers to their implantation and the solution to overcome them.

To conclude of the event, the Chair MEP Paul Rübig expressed his gratitude to EBC and its Members for their high-quality work and gave the opportunity to the European Parliament to have the support of prominent experts in the field of addiction.



COLLABORATION

Technological innovation strategies in substance use disorders - STOA Report



STOA Panel, Strasbourg, 19th February 2016

Responsible use of Animals in Research

Animal research regulations vary world-wide. In the European Union, Directive 2010/63/EU on the protection of animals used for scientific purposes replaced the EEC Directive from 1986 thus strengthening legislation, by improving the welfare of those animals that still need to be used, as well as firmly anchoring the principle of the Three Rs, to Replace, Reduce and Refine the use of animals, in EU legislation. The Directive is world leading on the protection of animals used in research.

The European Citizens' Initiative "Stop Vivisection" has been submitted to the European Commission on 3rd March 2015 and called for "the European Commission (EC) to abrogate directive 2010/63/EU on the protection of animals used for scientific purposes and to present a new proposal that does away with animal experimentation".

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.

EBC has joined a wide coalition of organizations expressing support in the current legislation and in becoming a member of an informal body European Life Science Alliance (ELSA). ELSA is a collaborative platform for organisations across Europe who have an interest in a scientifically and ethically justified use of animals in biomedical research. This includes, but is not limited to, both national and European research organizations, pharmaceutical bodies and health related charities.

As one of the first actions, along with 166 other signatories, EBC signed a statement prepared by Wellcome Trust that supports the current Directive. An extensive campaign addressing the European Commission and the European Parliament had been subsequently conducted by EBC, EBC members, as well as ELSA members. It culminated in a public hearing that has been held in the European Parliament in May 2015 and an official response from the EC published a month later.

While the Commission rejected the idea of abrogating the directive, it announced that by end of 2016 it would organise a conference engaging the scientific community and relevant stakeholders in a debate on 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.

COLLABORATION

Responsible use of Animals in Research

EBC has taken part in a number of initiatives in 2016 in a run up to the Conference. This involved coordinating with its members the EC relevant consultations, attending “workshop on implementation of Directive on the protection of laboratory animals – Focus on 3 Rs provisions” in February and participating in the ELSA London meeting in the same month, special lecture: “Animal Research in Europe - landscape and challenges” during the congress of Federation of Laboratory Animal Science Associations (FELASA) in June 2016, the meeting in the European Parliament in November that was proceeding the EC conference, Brussels symposium ‘Phasing out animal experiments, the next steps” in December and finally the EC conference itself “Non-Animal Approaches - The Way Forward” that took place on 6th-7th December in Brussels.

The Commission will publish the Report of the conference that is likely to influence the public dialogue during the months leading up to the publication of the Directive's review findings (November 2017) as well as the long-term strategy. EBC together with ELSA has been in contact with the EC in order to ensure that the report reflects as accurately as possible the outcomes of the conference.

EBC will be following this case very closely next year and we will report back on the progress in the 2017 annual report.

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SVI EP Public Hearing

COLLABORATION

Scientific Congresses

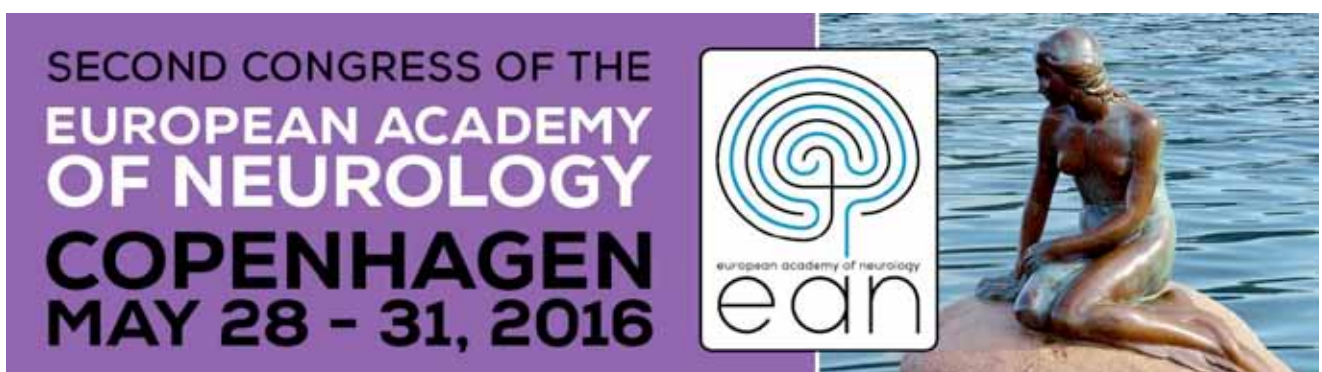
EPA

The annual European Psychiatric Association (EPA) congress, the 24th European Congress of Psychiatry, was held on 12-15th March 2016 in Madrid, Spain. 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 2016 congress was "Towards a common language in European psychiatry", which covered the newest psychiatric achievements: basic, clinical and translational research, and their application to evidence-based practices in diagnosis, treatment and education.



EAN

The 2nd Congress of the European Academy of Neurology (EAN) took place in Copenhagen, Denmark from 28th-31st May 2016. The programme included a series of innovative teaching courses, lectures, exhibitions and scientific exchanges.



COLLABORATION

Scientific Congresses

FENS

The 10th Federation of European Neuroscience Societies (FENS) Forum of Neuroscience 2016 took place on 2-6th July 2016 in Copenhagen, Denmark. The event gathered thousands of participants, ranging from top experts in the field, mid-career scientists, post-docs and students, facilitating and promoting the exchange of knowledge and neuroscience research.

On 3rd July, EBC and FENS organized special interest event on "Consensus Statement on European Brain Research: the need to expand brain research in Europe".



EBC Social interest event, Copenhagen, 3rd July 2016

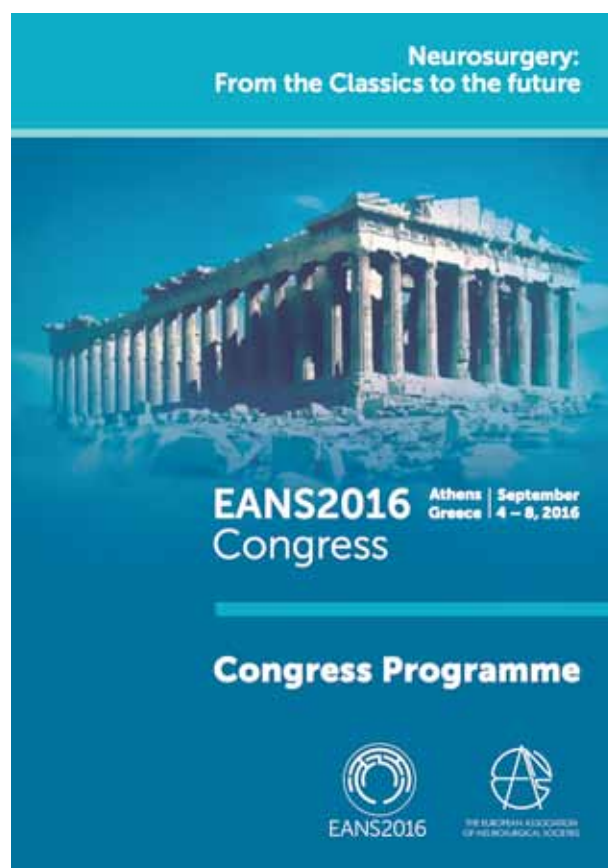
COLLABORATION

Scientific Congresses

EANS

The European Association of Neurosurgical Societies (EANS) 16th European Congress of Neurosurgery, took place in Athens, Greece, from 4th-8th September 2016. The meeting theme was "Neurosurgery: from the Classics to the future", which explored the past, present and future of neurosurgery and took an in-depth look at how far the field has come, where it is at now and what may lie ahead.

The programme aimed to provide an ideal opportunity to reconnect and share knowledge, whilst enhancing skill sets and improving patient care.



COLLABORATION

Scientific Congresses

ECNP

The 29th Annual ECNP Congress took place on 17th-20th September 2016 in Vienna, Austria. The congress attracts up to 6000 delegates, and is the largest European congress on major psychiatry and neuroscience. The congress consisted in a programme containing symposia, industry sessions, poster sessions, lectures, and a large exhibition space.



EBC MEMBERS & PARTNERS



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 / @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 / @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 it 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 / @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 / @ECNPtweets

EBC MEMBERS & PARTNERS



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

www.europsy.net / @Euro_Psychiatry



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

www.fens.org / @FENSorg



The **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.

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.



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.

EBC MEMBERS & PARTNERS



International Federation of Clinical Neurophysiology

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



The **European 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.



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.



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.



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.



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.

Joining on 1st January 2017

EBC MEMBERS & PARTNERS

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

EBC MEMBERS & PARTNERS

Industry Partners

abbvie



BIOMARIN



Joining on 1st January 2017

MEMBERS' HIGHLIGHTS

MEMBERS' HIGHLIGHTS

EPA

With the aim of fostering a better dialogue among key experts in the field of health and social care, the European Psychiatric Association successfully hosted its first Policy Event in Brussels, **"From policies to practice - from practice to policies: Creating synergies for better health in Europe"**. Through this event, which took place on **9th December** at the University Foundation, EPA gave particular attention to two main topics that are high on the EU agenda: integrated health care and mental health in the workplace. In addition to **EPA leaders, high-level representatives from European Institutions, (mental) health professionals, academics, patients and civil society** gathered together to discuss relevant EU policy developments in these areas and exchange on possible solutions for better health and health care in Europe.

EPA hopes that these efforts, along with the inter-sectoral collaboration promoted through events like this, will lead to the creation and implementation of comprehensive health policies throughout the EU.

The policy event, chaired by **Wolfgang Gaebel** (EPA President), **Manuel Martín Carrasco** (Chair of the EPA Council of National Psychiatric Societies/Associations) and **Silvana Galderisi** (EPA President Elect), opened with presentations addressing integrated health care and chronic diseases:

- "The EU Action on Chronic Diseases and the place of mental health" (Martin Seychell, Deputy Director General, European Commission, DG Health and Food Safety)
- "Patient empowerment in chronic disease management" (Hilkka Kärkkäinen, President, GAMIAN-Europe)
- "Integrated care: Towards better health for all" (Wolfgang Gaebel, EPA President)
- "Closing the treatment gap in brain diseases" (Patrice Boyer, Vice President, European Brain Council)

And followed with:

- "Promoting health, preventing disease. The economic case" (David McDaid, Research Fellow in Health Policy and Health Economics, London School of Economics and WHO-European Observatory on Health Systems and Policies)
- "Mental Health in the EU-Strategic Framework on Health and Safety at Work" (Jorge M. Costa-David, Policy Officer, Unit Health, Safety and Hygiene at Work, European Commission, DG Employment, Social Affairs and Inclusion)



EPA Policy Event, Brussels, 9th December 2016

MEMBERS' HIGHLIGHTS

Brain, Mind and Pain

The MEPs Interest Group on Brain, Mind and Pain is an initiative of EBC's member the European Federation of Neurological Associations (EFNA) together with the Pain Alliance Europe (PAE).

The Interest Group is co-chaired by MEPs Marian Harkin, Jeroen Lenaers and Daciana Sârbu, and aims to encourage research in and access to innovative treatments, promote prevention and self-management approaches, decrease stigma and work together to improve quality of life for people living with these disabling conditions.



Brain, Mind and Pain:
Interest Group on Brain, Mind and Pain,
European Parliament, Brussels, Belgium,
29th November 2016,

MEMBERS' HIGHLIGHTS

Mental Health, Wellbeing and Brain Disorders

Re-launched by GAMIAN-Europe in November 2014, the MEPs Interest Group on Mental health, Well-being and Brain Disorders is co-chaired by the MEPs Heinz K Becker, Cristian Silviu Busoi, Nessa Childers, Marian Harkin, Jean Lambert, Sirpa Pietikainen.

The Interest Group continues to raise awareness within the EU Institution on the importance of addressing mental conditions through the organisation of high level meetings on key issues such as Mental health in children and adolescents, Depression, Schizophrenia, Community and family care provision.



Mental health and wellbeing: Interest Group on Mental health, wellbeing and brain disorders, European Parliament, Brussels, Belgium, 13th July 2016

STAKEHOLDERS' HIGHLIGHTS

The background of the slide is a close-up, high-contrast photograph of crumpled white paper. The paper is folded and creased in various directions, creating a complex, organic pattern of light and shadow. The lighting is soft, highlighting the texture of the paper and the sharpness of the folds. The overall effect is one of movement and depth, providing a clean yet dynamic backdrop for the text.

STAKEHOLDERS' HIGHLIGHTS

MENTAL HEALTH COMPASS

From 5th-7th October 2016, EBC took part in three days of Mental Health and Wellbeing meetings in Luxembourg.

The Governmental Experts on Mental Health meeting, which gathered EU Member States and select country representatives, Mental Health experts and relevant NGOs took place on 5th October 2016. EBC's new Not Myself Today initiative was recognized and highlighted as an up and coming Mental Health in the Workplace initiative, with Executive Director Frédéric Destrebecq presenting the campaign to the room.

On the 6th-7th October 2016, the first Annual EU Compass Forum on Mental Health and Well-being took place in Luxembourg, organized by a Consortium led by the Trimbos Institute in the Netherlands, NOVA University of Lisbon, the Finnish Association for Mental Health and EuroHealthNet under the EU Health Programme (2014-2020).

The Forum brought together policy-makers from different sectors, Member State representatives, non-governmental stakeholders such as advocacy, professional, service provider, users and carers, trade unions and employers, and private sector organisations, and academic/research institutes, with the purpose to the progress in the implementation of policy recommendations from the Joint Action European Framework for Action on Mental Health and Well-being, to present an overview of good practices across the EU, and to address emerging issues such as the mental health of refugees.

The focus of the 2016 Forum was the prevention of depression, the promotion of resilience, and improving access to mental health care.

EU Compass Forum
on Mental Health,
Luxembourg,
5th-7th October 2016



STAKEHOLDERS' HIGHLIGHTS

SOCIETAL IMPACT OF PAIN SYMPOSIUM 2016

On 23rd and 24th May 2016, EBC participated to/attended the Symposium on the "Societal Impact of Pain" (SIP) that was held in the European Parliament and Concert Noble in Brussels.

Once again, SIP succeeds in gathering experts from all around Europe with the aim of reinforcing the EU legislation addressing pain treatments. In fact, *"Member States have been very slow to properly implement the Cross Border Healthcare Directive"* explains the MEP Marian Harkin *"patients must be provided with information to be able to make appropriate choices and doctors must be given the tools to assess the degree of pain being experienced by patients"*

"The prevalence of chronic pain, its societal and economic impact, and the clear deficiencies in pain care should be a wake-up call to policy makers"

The event was organized by the European Pain Federation EFIC and held under the high patronage of the Italian Ministry of Health and supported by the Interest Group on Brain, Mind and Pain and 20 cross-party cross-country Members of the European Parliament: Clara Eugenia Aguilera Garcìa, Heinz K. Becker, Soledad Cabezòn Ruiz, Nicola Caputo, Theresa Griffin, José Inácio Faria, Takis Hadjigeorgiou, Marian Harkin, Merja Kyllönen, Giovanni La Via, Jeroen Lenaers, Roberta Metsola, Miroslav Mikolášik, Piernicola, Pedicini, Sirpa Pietikainen, Sabine Verheyen, Francoise Grossetête, Therese Comodini, Cachia, Miriam Dalli, Agnes Jongerius and Alfred Sant.



SIP Symposium, Brussels, 23rd-24th May 2016

STAKEHOLDERS' HIGHLIGHTS

SOCIETAL IMPACT OF PAIN SYMPOSIUM 2016

SIP 2016 hosted four working groups discussing four key issues related to the societal impact of pain:

1. Pain as a quality indicator for health care
2. Chronic Pain: a disease or multi-morbidity?
3. The relevance of pain in cancer care and rehabilitation
4. Pain, rehabilitation and reintegration of workers in the working force

The faculty of each working group produced specific policy recommendations addressing the societal impact of pain to fundamentally change pain care and the effect of pain on society:

- Implement article 8.5 of the Cross-border Healthcare Directive
- Establish an EU platform on the societal impact of pain
- Integrate chronic pain within EU policies on chronic diseases
- Ensure that pain care is a part of policies and strategies on cancer
- Initiate policies addressing the impact of pain on employment
- Implement workplace adjustments for people with chronic pain
- Increase investment in pain research
- Prioritise pain within education for health care professionals, patients and the general public

SIP 2016 brought together over 220 representatives of health care and stakeholders-organisation from all over Europe, including scientific researchers, policy makers and patient representatives, and was endorsed by more than 160 international and national pain advocacy groups, scientific organisations and authorities.

As promised by Albert Sant MEP, and former Maltese Prime Minister president, SIP 2017 was confirmed and will take place in Malta, the 7th-9th of June 2017, under the financial support of the Maltese Ministry for Finance and with the auspices of the 2017 Maltese Presidency of the Council of the European Union.



STAKEHOLDERS' HIGHLIGHTS

CHILDHOOD DEMENTIA WORKSHOP

EBC attended and endorsed an event "Childhood Dementia Creating a Framework for Diagnosis, Care and Treatment" that took place in the European Parliament on 15th June. The aim of this event was to launch a Call for Action to improve the outcomes of patients suffering from Childhood Dementia. Dementia manifests itself through the unexpected deterioration of brain function. This is a manifestation most often associated with adult diseases such as Alzheimer's disease, and is often overlooked with regards to the diseases affecting children. Neuronal Ceroid Lipofuscinoses, Mucopolysaccharidoses and Leukodystrophies are diseases which can present with symptoms of Childhood Dementia. Continuing to fund breakthrough research into Childhood Dementia is essential to develop new treatments for patients.



MEDIA REPORT

Reports

Health & Social Care News



Brain disorders and the burden of diseases

26/09/16

Frédéric Destrebecq, Executive Director, and Vinciane Quoidbach, Public Health and Policy Project Manager at the European Brain Council, explain the socio-economic impact of interventions and the importance of early diagnosis with regard to brain disorders...

Depression, stroke, dementia, alcohol dependence, schizophrenia or anxiety will affect at least one in three European citizens during their lifetime – currently 165 million people in Europe (estimated 38.2% of the EU population annually)¹. Brain disorders are highly prevalent medical conditions, being the seat of many chronic disabling diseases²; today, mental disorders and other brain disorders represent 35% of the burden of all diseases in Europe³. Out of 10 individuals with a brain disorder, from 3 to 8 remain untreated although effective treatments exist⁴. And the burden of diseases is increasing.

The relentless demand for healthcare services is set to continue

Adjacent Government, "Brain Disorders and the burden of diseases", September 2016

Frédéric Destrebecq and Vinciane Quoidbach explain the socio-economic impact of interventions and the importance of early diagnosis with regard to brain disorders.

EAN Pages, "Interview with David Nutt", October 2016

INTERVIEWS • FEATURED SLIDER

Interview with Prof. David Nutt – President of the European Brain Council (EBC)

October 1, 2016



David B. Vodusek (DV): EFNS has been a founding member of EBC, and its successor EAN continues to be an actively involved member society. Nevertheless, many of our readers would appreciate to hear your views on what is EBC, its mission and how it gets this accomplished?

David Nutt (DN): The ultimate reason behind all EBC actions is to improve the condition of those living with brain disorders and to reduce prevalence of brain diseases all together. We realize it by advancing understanding of the healthy and diseased brain and by maintaining the constant dialogue between science & society. EBC has established its strategy on three main pillars: i) awareness raising & education, ii) improved treatment, prevention & health promotion, and iii) strengthened research. From this strategic outline come all EBC projects and activities. Crucial and underlying aspect of our work is an effective collaboration amongst member organisations within EBC in order to produce meaningful outcomes.

DV: Can you illustrate with an example how EBC's actions have influenced a significant change at the European level with regard to Europe's brain health?

DN: A concrete example of a joint success that EBC contributed to is the massive increase in public funding for brain research within the successive European Commission's framework programmes (FP). Whilst the "brain" was allocated a mere € 115 million in a pre-EBC time under FP5, it has now reached the bar of € 3.1 billion under FP7.

"The ultimate reason behind all EBC actions is to improve the condition of those living with brain disorders and to reduce prevalence of brain diseases all together"

"EBC is a coalition. There is strength in the range of professional and patient groups represented, giving a clear mandate to the work of EBC and weight to EBC's contribution"

MEDIA REPORT

Reports

Brussels Airline Magazine, "Not Yourself Today?", October and December 2016

"European companies and organisations will receive tools to organise events that will engage employees, getting them to pledge their support"



La Libre Belgique, December 2016



"1 out of 3 people suffers from Brain disorders today. That's why we are called to act"

The Guardian, "I put Myself in Standby Mode: What makes a survivor?", January 2017

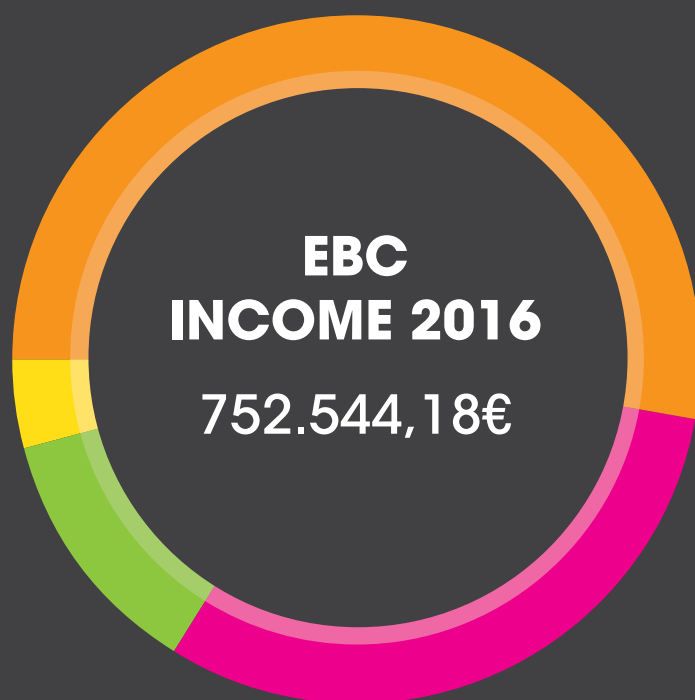
"Traumatic brain injuries, mental illness and cognitive disorders are likely to afflict more than a third of EU citizens, 179m people. They cost Europe €798bn [£668bn] a year, more than any other medical area" D. Nutt

"Understanding and promoting resilience is therefore both socially and economically wise. But can we do things to increase our resilience?"

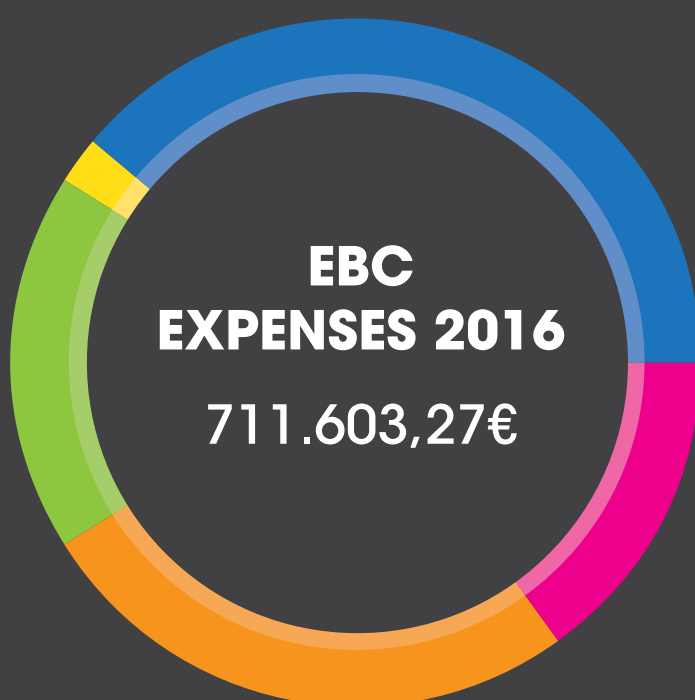
FINANCIAL DATA

Reports

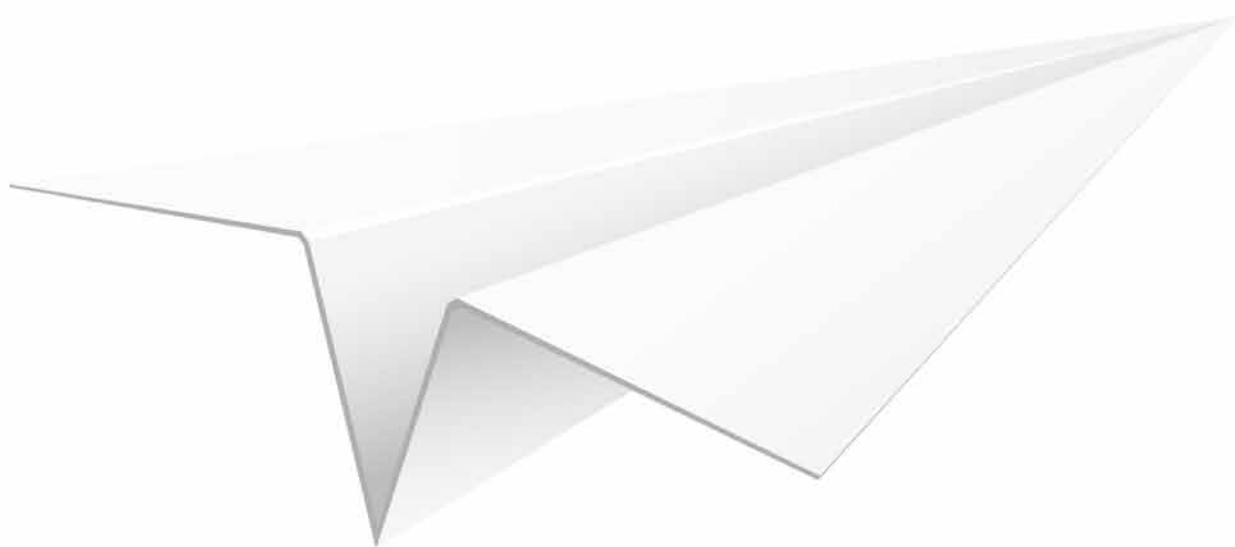
Membership Fees	53%
EBC projects (non EU-funded)	31%
EU funded projects	12%
EBC activities	4%



Team costs	39%
Meeting travel accommodation	15%
Services	26%
Advocacy and communication	18%
Other	2%



EBC EXECUTIVE & BRUSSELS OFFICE



EBC Executive

EBC Brussels Office



Prof. David Nutt
President



Frederic Destrebecq
Executive Director



Prof. Patrice Boyer
Vice-President



Giovanni Esposito
Research Project Manager



Prof. Monica Di Luca
Vice-President



Cécile Grebet
Finance & Administration
Manager



Prof. Wolfgang Oertel
Treasurer



Tadeusz Hawrot
Senior Policy Officer



Stephanie Kramer
Project Development
Assistant



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

The progress achieved in 2016 was made possible by the great efforts of EBC's Executive as well as the team at our Brussels Office.

Annex Meetings

- Meeting with Marek Plura MEP, 13th January 2016
- Meeting with Kilian Gross DG CNECT, cabinet of Commissioner Oettinger, 25th January 2016
- Meeting with Janusz Bujnicki, member of the High Level Group | The Scientific Advice Mechanism, 28th January 2016
- Netherlands Presidency event: Living well withouth dementia, 9th-10th May 2016
- Not Myself Today Introduction, DG Human Resources, 8th June 2016
- Not Myself Today Partners Meeting, University Foundation, 15th June 2016
- Not Myself Today Advisory Committee Meeting, 16th June 2016
- Meeting with Bogdan Wenda, MEP, 21st June 2016
- Meeting Sirpa Pietikainen, MEP, 22nd June 2016
- Lundbeck Patient Advocacy Summit (Copenhagen, Denmark), 28th-29th June 2016
- Meeting with research attache, Permanent Representation of Poland to the EU, 24th June 2016
- European Parliament Interest Group on Mental Health, Well-being and Brain Disorders meeting: "Mental health and brain disorders: Ensuring joint EU and national level action", 13th July 2016
- Not Myself Today Introduction, DG Employment, 20th July 2016
- Meeting with DG RTD – Maria Vidal and Karim Berkouk, 29th August
- Meeting with Dusan Sandor – research attaché from Permanent Representation of Slovakia to the EU, 31st August 2016
- EFPIA EBC Meeting re. IMI with Magda Chlebus, Science Policy Director, 31st August 2016
- Expert Platform on Mental Health meeting, 27th September 2016
- OECD EBC meeting with Emily Hewlett from Mental Health department, 16th September 2016
- Meeting with Karina Angelieva – Bulgarian Permanent Representation to the EU, 22nd September 2016
- Governmental Expert Group on Mental Health, DG SANTE, Luxembourg, 5th-6th October 2016
- First EU Compass Forum on Mental Health and Well-being, Luxembourg, 6th-7th October 2016
- Mental Health Europe event 'World Mental health Day': Mental health and young people in the digital age – addressing risks, seizing opportunities, European Parliament, 10th October 2016
- International Labour Organisation (ILO) Expert Meeting on Mental Health at Work (Geneva, Switzerland), 11th October 2016
- ENVI Committee workshop on 'Living with a brain disorder: Taking control of your life', 12th October 2016
- 3rd European Business Leadership Forum – Mental Health in the Workplace (London, UK) 19th October 2016
- BAE Systems Strategy Session: Building A Sustainable High Performance Culture (London, UK), November 21st 2016

Annex Meetings

- Meeting with Maltese ambassador Ray Azzopardi, 22nd November 2016
- City Mental Health Alliance - Annual Celebration Event at Bloomberg (London, UK), November 23rd 2016
- Meeting with WHO Representative Leen Meulenbergs, 24th November 2016
- Brain Mind Pain Breakfast Meeting, European Parliament, 28th November 2016
- STOA: Understanding the Human Brain - A new era of big neuroscience, 29th November 2016
- Alzheimer conference Bratislava Alzheimer's disease - the epidemic of the third milenium. Are we ready to face it?, 29th November
- Belgian Stroke Council International Symposium, 3rd December 2016
- Not Myself Today Introduction & Mental Health Discussion with MEP Miriam Dali's team, 2nd December 2016
- Pfizer-BMS Global Undiagnosed Atrial Fibrillation (AF) Advocate Advisory Board (Amsterdam, Netherlands) 5th-6th December 2016
- European Commission Scientific Conference: Non-Animal Approaches - The Way Forward, 6th-7th December 2016
- EPA Policy Event "From policies to practice - from practice to policies. Creating synergies for better health in Europe", 9th December 2016

Annex of Speakers at EBC Board Meetings

2016 Board Meetings Speakers List for Annual Report

BM1: 17TH-18TH FEBRUARY, 2016

Board Dinner

Baroness Françoise Meunier, Director Special Projects, European Organisation for Research and Treatment of Cancer (EORTC)

Topic: Challenges and opportunities of clinical research in Europe – The EORTC perspective

Mr Guy Dargent, Scientific Project Officer, European Commission, Consumers, Health, Agriculture and Food Executive Agency (CHAFEA)

Topic: Developing the European Programme of Action Against Cancer – Could this be inspirational for brain diseases?

Annex of Speakers at EBC Board Meetings

Mr Denis Horgan, Executive Director, European Alliance for Personalized Medicine (EAPM)

Topic: Personalized Medicine in Europe – Does it matter for brain disorders?

Board Meeting

Ms Jean Mossman, Healthcare Consultant

Topic: Advanced HTA

Prof. Crispin Jenkinson, Professor of Health Services Research & Director of the Health Services Research Unit, University of Oxford and Prof. David Morley, Senior Research Scientist, University of Oxford

Topic: Ox-PAQ 1 & 2

BM2: 25TH-26TH MAY 2016

Board Dinner

Mr Xavier Prats-Monné, Director-General, European Commission, Health and Food Safety (SANTE)

Topic: Priorities in public health with focus on the brain

General Assembly

Dr Ruxandra Draghia-Akli – Director for Health Directorate, DG Research

Topic: “Lunch discussion”

Prof. George Gaskell, Professor, London School of Economics

Topic: Presentation on the outcomes of the NERRI project

Mr Robert Madelin, Senior Innovation Adviser, European Political Strategy Centre

Topic: “In conversation with..”

BM3: 28TH-29TH SEPTEMBER 2016

Strategic Workshops, Day 1: VOT

Dr. D. Furby, Fipra International

Topic: The Value of Health: Improving Outcomes

Annex of Speakers at EBC Board Meetings

Board Dinner

Sir Colin Blakemore, School of Advanced Studies, University of London

Topic: "The role of EBC ambassadors: advocating for Brain Research in Europe"

Mr Christoph Ebell, Human Brain Project

Topic: "The Human Brain Project: recent developments and perspective for the future"

Prof. Juan Lerma, San Juan de Alicante Neuroscience Institute

Topic: "Challenges to brain research: the case of ethical animal use"

Strategic Workshops, Day 2

Prof. Holm Graessner, Centre for Rare Diseases, University of Tübingen

Topic: "The launch of European Reference Networks: new prospects for quality care in Europe"

Dr. Mary Baker, EBC President (2010-2013)

Topic: "EBC Advocacy: the lessons learned from the Year of the Brain"

Prof. Hartwig Siebner, Danish Research Centre for Magnetic Resonance

Topic: "Developing an EU population neuroscience strategy"

Mr Christoph Thalheim, European MS Platform Secretary General

Topic: "Data collection and patient registries: the example of Multiple Sclerosis"

Dr. Matilde Leonardi, Fondazione IRCCS Istituto Neurologico Carlo Besta

Topic: "The omnipresent brain in our life course and the determinants of its health: prevention, promotion, and treatment"

Mr Jain Mohit, Biomarin

Topic: Childhood dementia

BM4: 30TH NOVEMBER 2016

Board Meeting

Dr. Andrzej Rys, Director for Health Systems, Medical Products and Innovation, DG Santé, European Commission

Topic: "In conversation with.."

Annex of Speakers at EBC Board Meetings

Lunch

Ms Sophie Dix, Director of Research, MQ: Transforming Mental Health

Topic: Introducing MQ

Prof. Hans-Joachim Pflüger, International Brain Research Organization (IBRO)

Topic: Introducing IBRO-PERC

Board Dinner

Mr Omar Cujatar, Research Attaché, and Mr Stephen Mifsud, Health Attaché, EU Permanent Representation of Malta

Topic: Priorities of the incoming Maltese presidency of the EU

CREDITS

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



Graphic design by Cookdesign srl

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with best practice guidelines of visual accessibility.

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for maximising the readability of our publications.

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